

To Know Their Stories:

Using Playbuilding to Develop a Training/Orientation Video on Person-Centred Care

Kevin Hobbs

Social Justice and Equity Master's Candidate

Submitted in partial fulfillment of the requirements for the degree of

Master of Arts

Faculty of Social Sciences, Brock University St. Catharines, Ontario

© 2019

Dedication

To my mother and father. You go on long after your last breaths were released. I hope I've honoured your teachings through my own approach to life.

Abstract

This study explores the experiences of health care staff and family members who provide support for people living with dementia and traumatic brain injury. Using a playbuilding methodology (Belliveau, 2006; Norris, 2009; Perry, Wessels & Wager, 2013) in which theatre performers devised short vignettes based on focus group interviews with health care providers, an educational video was produced. The video will be shown to the focus group interviewees in order to generate further conversation—knowledge co-creation—on the supportive and resistive practices in person-centred care (Leplege, Gzil, Cammelli, Lefevre, Pachoud & Ville, 2007; Kadri, Rapaport, Livingston, Cooper, Robertson & Higgs, 2018; Santana, Manalili, Jolley, Zelinsky, Quan & Lu, 2018), a philosophical approach that privileges the holistic needs of the individual rather than the bio-medical and administrative urgencies of the medical system. I outline the process of developing vignettes, videoing them and editing the video using a constructivist approach and an application of narrative and film theory. This work adds to the discussion of how the health care system may benefit from arts-based methods of knowledge construction.

Keywords: playbuilding, person-centred care, arts-based research, dementia, traumatic brain injury

Acknowledgements

Thanks to my committee members who have supported my creative spirit and invested in me an essential rigour to this work. Thanks to my supervisor, Joe. We share more than a birthday but a sense of play. Your mentorship has been brilliant. I appreciate the faith and openness provided by Leanne Hughes and Dr. Colleen Whyte, who allowed me to participate in this project and who entrusted me to develop this video. I gratefully acknowledge the talent and energy of the Mirror Theatre cast: Lindsey Abrams, Dani Shae Barkley, Lindsay Detta, Nadia Ganesh, Bernadette Kahnert, Rosa Moreno, Mike Metz, Abby Rollo, Sumer Seth, Dawson Strangway. Talk about talent and commitment. My appreciation to Brad McDonald who filmed and co-edited the video. I am indebted to the Department of Dramatic Arts, Brock University where much of the creativity took place and to the Social Justice and Equity Program, including Mary-Beth Raddon and Ferdinand Reimmer. Thanks to my brother and sister: we rode out some tough times together. Finally and most importantly, my unbounded gratitude to my wife, Monica. You've navigated books and papers scattered throughout the house, sticky notes in the oddest of places and my occasional bouts of uncertainty and stress. Couldn't have done this without you.

Table of Contents

Dedication	i
Abstract	i
Acknowledgements	ii
Chapter 1: Introduction	1
Stories = Data	5
Story Generation = Data Collection	6
Mediate = Analyze	6
Ethics, Benefits and Risks	9
Bracketing In	11
Chapter 2: Literature Review	14
A Brief History of Western Medicine	14
Patient	20
Patient-Centred Care, Person-Centred Care and Narrative	21
Dementia, Traumatic Brain Injury and Responsive Behaviours	28
Social Justice in Health Care	29
Chapter 3: Methodology and Methods	34
Methodology	34
Playbuilding	36
Methods	41
Story Generation and Devising	42
Metaphor	50
Shadow Screen	51

External Sources	54
Videoing	55
Sequencing for Editing	56
Point-of-View	59
Dissolve	60
Chapter 4: Transcript	61
Chapter 5: Conclusion.....	93
Transcript Reflections	93
Breakfast offerings. 7:14-9:24.....	93
Mis(sed) understanding. 18:32-19:53.....	94
Should it be normal? 22:10-23:41	96
Next Steps	97
Knowing more stories, finding deeper relationships	97
Two future workshops	99
Defining Person-Centred Care.....	101
A Personal Summary	103
References.....	106
Appendix A: Transcript Responses	117
Appendix B: Log Book/Journal	127
Appendix C: Shot List	139
Appendix D: Editing Notes and Sequencing	141

Chapter 1: Introduction

In the early part of the twenty-first century I was teaching in the Standardized Patient Program at the University of Toronto as a medical educator, working with medical students and recent graduates on effective communication skills. I was particularly focused on the strategies of diagnostic inquiry. Simply put, we explored in class what might be the most effective way for a doctor to converse with a patient to find out what's going on. In order to assist in this training, the standardized patient program developed a tool to assist learners in conceptualizing different communication approaches. It was a single piece of paper known as the University of Toronto SPP Observation Guide (Physicians Apply, n.d.) and on it were three domains that could be applied to a communication context: Techniques, Styles and Attitudes. Through this guide learners could reflect upon the communication approaches they employed as well what approaches they observed in other learners.

Techniques referred to tools that might be used in a verbal exchange, such as *clarifying*, *summarizing* and *asking permission*. These were concrete measures that were easily identifiable to most learners. *Styles* considered the *how* in a communication process, and the Observation Guide provided examples such as speech pattern and questioning style. The domain of Styles reflected upon a communicator's behaviour. Finally, at the bottom of this single page was *Attitudes*. Attitudes referred to a communicator's point of view, values and cultural background. Attitudes was placed at the bottom of the page acting as symbolic foundation for the other two domains, as it was believed, in the development of this guide, that behaviours and choices of tools materialized from an individual's identity (Johe & Bhullar, 2016; Toomnan & Intaraprasert, 2015). In order for a doctor to understand why she asked a series of closed-ended questions

(which could provide specific yet limited responses), that doctor might want to self-reflect on their deeper influences. Was this close-ended form of questioning a practical response to external circumstances (eg., it is an emergency and time is of the essence) or a response to an internal driver (eg., a doctor's general dislike for lengthy discussions with patients)? Attitudes was the most difficult domain to discuss with the learners, and often it was avoided during feedback sessions.

Since my time at University of Toronto I have often mused on the challenges of exploring with learners concepts of attitude. It is no easy subject to rummage through since such an exploration might open up a can of worms. It might bring to light uncomfortable truths about oneself. It might reveal vulnerability within a learner who is training to be a strong and supportive healer/helper/guide. It is easier to deflect and concentrate on the vulnerability of the patient, one who has expressed need for assistance. It is less complicated to centre care on the patients—and hear their stories—rather than the stories of all people who are involved in a health care interaction. To me, this single-direction administration of care leaves those who provide critical services in the health world more vulnerable than ever. When do they get to tell their stories?

The principle goal of my study was to create an educational video on approaches toward achieving person-centred care for people living with dementia and traumatic brain injury and, in doing so, explore the stories of health care workers and family members. Beach et al. (2016) demonstrate how a videotaped performance on cancer treatment created conversations among the viewers, a dialogic response (Pifarré, 2019) that deepened understandings through a collaborative means. This video shares those intentions, and has been developed to generate

dialogic opportunities through a series of embedded cues that shall be described in the upcoming chapters.

As I move through the thesis I shall be referring to specific vignettes within the video, and will provide a time code so that the reader may reference if desired. I have distributed these time codes throughout as opposed to containing them in a single chapter because of what has emerged from the study, which is that strong, human relationships are critical in health care, and that we can only really know one another by grappling with these relationships. Wilson (2008) states that “an idea is formed by relationships within a specific context” (p. 123), and argues that a linear, compartmentalized approach cannot necessarily support the needs for developing knowledge in a relations-based context. In order to keep the relationships alive in this document, thereby maximizing pedagogical opportunities, I have placed sections of the thesis in chapters that at first glance might seem out of place. I have done so for the sake of presenting context, perhaps even a conversation among seemingly disparate topics.

In order to contextualize my study I invite you to click on the link to the entire video which runs for thirty-two minutes and five seconds. If you are reading a hard copy of this study a dvd has been provided in a sleeve inside the thesis. I hope you will now take the time to view the video. Once you have completed the viewing please return to this point in the thesis and I will continue with my introduction.

Video Link: http://www.joenorrisplaybuilding.ca/?page_id=3004

This study is part of a larger project exploring the complexities of person-centred approaches in acute care in Sunnybrook Health Sciences Centre, a health complex in Toronto, Canada.

The larger project, named “Determining the Efficacy of Applied Theatre and Pedagogical Research-based Performance/workshops for Community Engagement and Professional Development Training”, was initiated by Leanne Hughes (Professional Practice and Education Leader for Recreation Therapy at Sunnybrook) who then invited Dr. Colleen Whyte (Associate Professor, Recreation and Leisure Studies, Brock University) and Dr. Joe Norris (Artistic Director of Mirror Theatre and professor of Drama in Education and Applied Theatre, Brock University) to participate as co-researchers. Hughes had been requested to design training opportunities for staff and faculty around person-centred care for individuals living with dementia. Funds for this project were provided by the *Practice-Based and Innovation Seed Grant*. As outlined by Hughes, Whyte and Norris in their grant application, the following research questions to be addressed were:

- 1. What are the current practices that support and/or resist person-centred care approaches from the perspective of patients, family members and staff?*
- 2. What are the conditions that support and/or challenge person-centred care? How do stakeholders negotiate identified challenges?*
- 3. What are the personal and professional tensions of practicing person-centred care?*
- 4. How can video vignettes enable patients, family members and staff to advance the principles of person-centred care?*

This project was divided into three phases. Phase #1 was comprised of four focus groups involving families and staff associated with Acute Care General Medicine at Sunnybrook. It concluded in the early months of 2019 by Hughes, Whyte and Norris. Phase #2 involved, through a playbuilding methodology, the mediation of the focus group stories which were then turned into theatrical vignettes, videotaped and edited into an educational video. Phase #3 is yet

to be completed. It will present the video to the staff and family members from the focus groups. Hughes, Whyte and Norris will then, through the assistance of the videos, explore with the viewers the new knowledge generated through this process.

This thesis describes my part in the study: Phase #2. I collaborated with members of Mirror Theatre, a local theatre company in St. Catharines, Ontario, Canada, to devise twenty-one vignettes over a period of five weeks, from March to mid- April, 2019, which were then videotaped (April 13) and edited throughout June and July by Brad McDonald, Joe Norris and myself.

I formed my research question from the first three questions of the larger research study, grounding my inquiry into the complexities of person-centred care. In order to consider current health care practices, systemic supports and institutional tensions, I asked the following: *What experiences do health care staff and family members have when caring for people living with dementia and/or traumatic brain injury, and what is the impact on staff and family when providing this care?* By pursuing this question the caregivers who may have been unable to share their stories would be provided an opportunity to do so.

Stories = Data

I, as well as others, consider *stories* to be the *data*. Connelly and Clandinin (1990) detail how, through narrative inquiry, stories become the “quality of experience to be studied” (p.2). In my thesis research, the original or primary data has been gathered through focus groups on person-centred care. Focus group interviewing is a research method that privileges the sharing of experiences through dialogue and story (White, Dangerfield II & Greib, 2019). Subsequently,

Mirror Theatre's company of actors dramatized the focus group transcripts (Saldaña, 2018) and new or secondary data—*new stories*— were generated in the form of theatrical vignettes.

Story Generation = Data Collection

I use the term *story generation* rather than *data collection* in order to minimize the “objective and pure” (USAI, 2012, p.7) philosophy dominating much of western research. “Objective” and “pure” suggest an end point, a pinnacle to be achieved, and this research does not seek a conclusion. Rather, this work attends to Dewey's (1938/1997) proposition of creating focused, progressive experiences based on earlier experiences in order to support ongoing dialogue. The excavation of the story may be bottomless. Neither does this research seek to organize information into data sets, a systemic approach that can compartmentalize knowledge and people into hierarchies (Smith, 2012, pp. 66-72) or privilege certain ways of understanding (eg., Empirical evidence) over other ways, such as cultural knowledges (Wilson, 2008, p. 58). The devised theatrical vignettes are responses to the stories in focus group transcripts. Those are two levels of stories, two kinds of data—primary and secondary—in western scientific terms. The vignettes will then be observed in video format by staff and family members at the originating health centre, Sunnybrook Health Sciences Centre. Upon the viewing of the videos (beyond the scope of the research for this thesis) undoubtedly more stories will result, more stratum of knowledge revealed.

Mediate = Analyze

In order to examine the stories I am choosing to use the term *mediate* rather than the more traditional *analyze*, a term closely connected to empiricism and its accompanying paradigm, positivism (Petrovich, 2018; Cresswell, 2014), which Smith (2012) describes as a

form of understanding that reduces the world to “issues of measurement” (Smith, p.44). Indick (2002) notes how a positivist reduction settles into a single, observable truth. The conundrum becomes, then, how can one adequately measure stories and then disseminate the findings to facilitate knowledge production? What positivist approach would be suitable or possible when exploring and discussing the complexity and uniqueness of the individual’s story (Charon, 2006)? Ayala and Zaal (2016) question traditional scientific methodology and observe how “words, neatly strung together in academic prose” (p. 2) are insufficient in conveying deeper, emotional meaning. Leavy (2015) encourages a directional change away from the restrictiveness of traditional research criteria, explaining how an arts-based research approach invites multiple voices, multiple perspectives, eschewing the singular, observable truth of positivism. Through the visual forms of drawing and painting, Fish (2018) uncovers a collection of understandings in the lives of underrepresented children. Salvatore (2018) may start with a single research question but his explorations through ethnodrama stimulate and embrace multiple meanings and experiences. Faulkner (2009) responds to complexity through the form of poetry, saying it:

“defies singular definitions and explanations, it mirrors the slipperiness of identity, the difficulty of capturing the shifting nature of who we are and want to be, and resonates more fully with the way identity is created, maintained and altered through our interacted narratives. (p. 100).

Fish, Salvatore, Faulkner and anyone engaged in arts-based research are facilitators of varied kinds of information and experiences, a kind of facilitation that Leavy recognizes as a challenge that “requires openness to the spontaneous and unknown” (p.20). Norris (2017) describes this multi-faceted challenge as an “intricate relationship to content” (p. 295) as a mediation. Being open to the dynamic interactions of the unknown in a structured way in order

to reconcile (or perhaps not reconcile) multiple meanings is a mediating act. It is for this reason I replace *analyze* for *mediate*. As stated by Beer and Steif (1997), mediation is not about determining the truth but rather it is about listening for “what matters to people” (p.5). It is about maintaining a “relational accountability” between community and that which is being researched. (Wilson, 2008, p.106).

On a final note, theatre has been preoccupied with the act of mediation, either embracing it through dramatic forms such as spectacle and its accompanying technologies, or reviling it by seeking a purity of naked presence, often literally (Copeland, 1990). Boal (1974/2008), as an interlocutor in a dialogic process, created discourse with the ultimate goal of “showing real things” (p. 145) rather than “revealing how things really are” (p.145). Simply put, Boal (1974/2008) wished to display rather than lecture, placing the power (and privilege) of interpretation onto the audience. Similarly, members of Mirror Theatre stood in the middle space, the ideas and emotional responses to health care from the focus groups on one side, their own ideas and emotional responses and perspectives of health on another, and external sources of information from a third side. Through the act of mediation they combined, defined and navigated the various concepts of person-centred care to show a reality for others to contemplate rather than tell them what it is.

My research process has two layers of mediation. The first layer is the shared exploration of the stories from the focus groups, in which members of Mirror Theatre reflected, improvised and devised scenes, allowing themes to emerge (Belliveau, 2006). The second layer of mediation is in the editing process, as it requires a second kind of analysis into the themes that emerge through the medium of video (Gubrium, 2009; Harris, 2017; Scarnato, 2019). These themes are

pedagogically relevant since the resulting video will be utilized to enhance person-centred care in the health care facility.

Ethics, Benefits and Risks

Hughes, Whyte and Norris applied for and obtained ethics approval from the research ethics boards of both Sunnybrook Health Sciences Centre where the focus group interviews took place and Brock University. My entry into the project necessitated a modification to the applications.

Ethical approval was required because of the human subject component in Phase# 1 of the larger research project – the focus group interviews of family members and Sunnybrook staff. These individuals were recruited by Hughes, Whyte and Norris and the process of informed consent was completed before the focus groups began. Phase# 2, my thesis research, was collaboration with Mirror Theatre and its performers, known as A/R/Tors (actors, researchers, teachers) (Norris, 2009). The A/R/Tors are credited in the script as co-researchers and co-authors.

With regard to informal ethical considerations, Mirror Theatre operates under the agreement of non-disclosure. What this means is that individual stories and opinions shared with the group are kept confidential, and utilized in sessions as frameworks to explore more deeply themes and metaphors. Identities of focus group participants have been replaced in the transcripts with letters or numbers in order to maintain confidentiality. The stories of the focus groups and the personal experiences and perspectives of A/R/Tors are interpreted, mediated, melded, told and re-told until the final scripts have distance from the original stories providing, as Norris (2019) says, “the anonymity needed to protect cast members and associated others” (p. 37). The

final video of the devised vignettes presents scenarios that may be familiar to focus group participants who happen to observe them, but are not identifiably representative of a particular individual. Mirror Theatre A/R/Tors, however, are both researchers and participants in the research and as such their identities are not kept confidential. Each A/R/Tor is recognizable on the video and their name is included on the list of vignette co-authors.

Risks were minimal in this research project. It may be that during the devising process an A/R/Tor remembered a negative event from a health care interaction (eg., the trauma of seeing a loved one in a state of delirium). Mirror Theatre's members are supported by one another and if professional help is required the member is supported and encouraged to seek that help. An A/R/Tor's revelations of personal health and well-being, as agreed upon by Mirror Theatre membership, are kept confidential. As it turned out, no company member has required support at the time of the writing of this thesis.

There are benefits to this research, including:

- Experience for Mirror Theatre members in research processes and arts-based methodologies, and an acknowledgment of this experience in a Master's thesis. Such an acknowledgment will contribute to the curriculum vitae of those seeking work in the field of applied arts
- Opportunity for Sunnybrook staff to explore deeper levels of understanding in communication skills and person-centred care ideals leading to increased competency in health care processes

Opportunity for the administration at Sunnybrook to reflect upon the kind of person-centred care it presently provides, and what changes it can implement to strengthen that care.

Following this introduction, chapter 1 of my thesis, I will move into chapter 2, a review of the literature. I provide a brief overview of western medicine, tracing lines of thought and philosophical approaches that led to evidence-based medicine (Webb, 2018), a clinical decision-making process. I consider the advantages and disadvantages of evidence-based medicine and this takes me into a review on patient and person-centred care (two philosophical approaches within medicine that prioritize collaboration and individualization of treatment) and narrative approaches within health care. I also spend time on discussing dementia, traumatic brain injury and responsive behaviours, which are a range of actions symptomatic of individuals living with dementia. Finally, I end the chapter reviewing the literature advocating for a social justice model of medicine. Chapter three is concerned with my methodological approach, playbuilding, and the methods employed to devise theatrical vignettes. I provide theoretical underpinnings and strengthen the argument as to why playbuilding is a methodology well-suited to this research, especially in its dissemination. As I elaborate on my process and the methods used for devising the vignettes and editing the video, I will discuss how decisions were made and will reference both the video and the transcribed script. Chapter four provides the full transcript of the video. Finally, chapter five concludes with a reflection on three of the vignettes, making explicit some of the connections and possible discussion topics in the forthcoming Phase #3 of this study. I also consider the next steps this research study could take, and where further exploration into person-centred care could lead. I end with a reflection of my personal journey throughout this study, contrasting my perspective before entering this research with the views I hold now. As Wilson (2008) asserts, good research changes the researcher (p. 135).

Bracketing In

Before continuing to the literature review, I believe it is appropriate to provide a brief description of my background to illustrate the experience I bring to this research and why I have chosen this line of research. In 1990 I began working professionally as an actor and – a few years later – as a playwright, writing several plays and appearing onstage in over thirty productions. Much to my surprise I came to the realization that the majority of my writing focused on social constructs, and my story-telling responses were attempts at challenging stereotypical notions on areas such as gender (Hobbs, 1995) and masculinity (Hobbs, 2000) by co-opting and undermining popular genres (eg., sex comedy, thriller). Dénommé-Welch (2008) in discussing his artistic practice and the work of other Indigenous artists, describes the potency of engaging the mainstream world and its mythologies in order to deconstruct. Reflecting upon my theatre preferences, I am more attentive to the ferocious dramas of Suzan-Lori Parks (Vanhoutte, 2017) and the marginal voices present in Michel Tremblay's plays (Bloom, 2015). Both these playwrights provoke and unsettle the spheres of collective dominance (Wolgemuth & Donohue, 2006).

As a playwright, I have generated the bulk of my scripts independently. My process often involved interviewing people, and it always included workshopping the scripts with actors in order to find dramatic sense. Although I have been involved in collectives where we devised scripts together, this study has been a unique and rewarding experience. I have had to learn how to receive, manage, juggle information from diverse sources, and have then facilitated this information in order to co-create an assortment of vignettes to which I can claim some but not all creative input. For me, it has been a new way to approach and develop material into theatrical form.

In 1998 I began another, parallel career in medical schools as an educator on effective communication skills. It is the *second hat* I wear. I trained health professionals through experiential methodologies, utilizing roleplay, observation exercises within large group scenarios, and simulation with mannequins. Moving past lecture-based teaching I worked with students, encouraging reflection, liminal learning and varied perspectives on the nature of good communication within the context of patient-centred care. As an educator I worked first in the department of Medicine at University of Toronto and later moved to McMaster University where I initiated and managed a Standardized Patient Program for two and a half years. During my time as a medical educator I became interested in how narrative and art can contribute to health care. I have presented medically-themed theatrical readings to bring awareness of patient and clinician struggles to health care students and conference attendees. I have spoken on simulation and patient-centred care in medical workshops, and taught group facilitation techniques at international health conferences. I have written two educational modules on how to provide feedback, one of which has found a home in an educational institute in China, while the other is available to an international membership of standardized patient educators. I often work with patients by gathering their stories and presenting them into educational opportunities for health care students. I recently co-authored a paper on the use of narrative when working with people who have intellectual and developmental disabilities (Coret, Boyd, Hobbs, Zazulake and McConnell, 2017). I am co-recipient of the 2010 Alan Blizzard Award for “exemplary collaborative projects that improve student learning.”

There is a *third hat* I wear – the hat of a son. My mother lived with Alzheimer’s for twenty years before passing away in 2017. Her last years were spent in a long-term care facility. I completed writing the first draft of this thesis two months after my father died. He was living in

the same facility as my mother, slipping in and out of delirium while coping with cognitive decline. Both my mother and father demonstrated responsive behaviours as their conditions progressed, and I spent much time with the support staff at the long-term care facility hearing about their struggles and the successes when caring for my parents.

These days the hats overlap. I continue to write plays (Hobbs, 2017; Illich, 2017) and am a member of Mirror Theatre. I recently attended the Curriculum and Pedagogy Conference as an educator and co-presenter with Joe Norris, devising with teachers a series of vignettes on early schooling experiences (Norris & Hobbs, 2018). I am researching the impact of medical roleplay on people with Intellectual and Developmental Disabilities. Fresh in my memory is the time I spent with my father and mother, witnessing and experiencing person-centred care, and noting at times its absence. It is through the combination of these three areas of interest—theatre, medical education, family—that I approach this research.

Chapter 2: Literature Review

This section will provide a review of the literature in domains relevant to my thesis: western medicine, concepts behind the term *patient*, person/patient-centred care and narrative, dementia and social justice. Emerging from the review is how disparate concepts of medicine serve to confound any kind of cohesiveness in patient care, leading to hierarchical rankings within the world of health. A consistent thread among the literature in this section is how narrative acts as a force for conceptualizing and reconceptualising health.

A Brief History of Western Medicine

Earlier, in “Terms and Definitions”, I delivered some short remarks on different interpretations of health. Now I shall expand by discussing concepts of western medicine. The

origins of western medicine are founded on the scientific investigations of the ancient mid-eastern cultures, the Greeks being most prominent (Fornaro, Clementi & Fornaro, 2009; Kanellou, 2004). Varied schools of thought endeavoured to reveal knowledge through an empirical approach, a methodology based on the principle of social experience (Leavy, 2015) and structured into protocols to determine indisputable truths through verification and reduction (Benjamin, 1954). The Methodic and Empiric schools emphasized *treatment of illness over cause*, eschewing any serious contemplation of “internal processes hidden from sight” (Balalykin, 2017, p.86) as these narratives were considered extraneous and would interfere with the diagnosis. In seventeenth century Europe, scientific reasoning developed structured approaches that included the ideals of rationalism and empiricism. English physician Thomas Sydenham (1624-1689) published texts advocating a direction in medicine that categorized diseases, their correlating symptoms and probable outcomes (Stewart, et al., 2006, p.19). This system for understanding disease endorsed *classification*, a methodology that supports a process of isolationism to achieve the “ultimate goal of predicting and controlling reality” (Wilson, 2008, p. 36).

Disconnection became a routine mode of thinking in clinical methodology, advocating the premise that disease is conceptually a thing located in the body, with its own story, and is separable from the person (Stewart, et al., 2006, p. 20). Sullivan (1986) provides an account of how medicine became fixated on Descartes’s mind–body duality and how through the nineteenth century, as the use of autopsies to understand disease increased, physical examination of the inner body gained prominence over a patient’s description of symptoms. This Cartesian approach flips the Methodic and Empiric schools on their heads as biological, bodily disease, the *cause*, became the narrative reality while symptoms, the *illness* or the “experienced sense of disability”

(Sullivan, 1986, p. 335) were merely manifestations of a mentally anguished experience. Descartes's duality (perhaps I should say duel-ity) reinforced disconnection in at least two philosophical arenas. The first arena involved western medicine's ongoing split of the interior (bodily disease) and exterior (patient's experience of symptoms). The second philosophical arena addressed the physician/patient relationship, in which the physician achieved primacy. Sullivan (1986) describes the confirmation of privilege this way: "the truth of patient's words is measured by physicians' eyes" (p. 336). Freidson (1985) calls it "professional dominance" (p. 13).

Physicians had been campaigning for social prestige at least as far back as the scientific revolution. Hierarchy was established through *profession* (Colson & Ralley, 2015). One example can be found in the development of pharmaceutical medicine. By controlling patient treatment "physicians prided themselves on using their learning to establish the 'correct' version of ancient medicines or to apply newly discovered drugs or plants" (Barry, 2018, p.160). Notable is the fact that seventeenth/eighteenth century medicine sustained a discordant relationship with the land, prospecting its natural benefits while advocating a metaphysical separation of the human from nature, and in doing so giving "man" *dominance over creation*. (Is there a more vivid narrative depicting the scientific urge to subjugate nature than Shelley's (1816/1983) *Frankenstein*?) This drive to dominate translated into a capitalist, profit-making model (LaMothe, 2013; McKee & Stuckler, 2012). The same impulse gave rise to the colonial interpretation of Indigenous people as commensurate with flora and fauna (Smith, 2012), leading to historic marginalization through medical strategies based on race and biology (Lux, 2001; Anderson, 2007). This marginalization is not relegated to the past. Ly and Crowshoe, (2015) report on how present-day medical school students uphold negative stereotypes of Indigenous people as reasons for health problems, while

Etowa, Jesty and Vukic (2011) found that Indigenous nurses in the Canadian health system can have troubling relationships with non-Indigenous colleagues and the overall Canadian system.

The tendency to dominate nature continues into the twenty-first century and beyond. Consider the recent rise of the transhumanism movement, in which technology is hypothesized as the pathway to the creation of a post-human being, one who exists beyond nature's limitations (Porter, 2017; Thompson, 2017). This movement seeks to transcend illness, physical and mental barriers, and even death. Rybin (2016) identifies the processes of transhumanism as a "purely reductionist approach to the individual" (p.30). Spirituality is eclipsed by reason, and relationships to the natural world are replaced by relationships with technology. The goal of transcendence fits sequentially into the philosophical objective of western medicine, identified by Broadbent (2018) as a Curative Thesis, a "claim that cure is the core medical competence" (p. 292). In other words, if there is no cure to the illness, if there is no conquest, then there is no medicine.

Before I move on from this brief history, there should be an exploration on a critical characteristic embedded in western medicine: "othering". Presently there is discussion in the health care world of *inclusionary othering* (stepping into another's shoes to achieve greater understanding) and *exclusionary othering* (manipulating power differentials in relationships to achieve dominance) as processes within health care (Canales, 2000). I am focusing on exclusionary othering due to its historical significance in medicine. Johnson, Bottorff, Browne, Grewal, Hilton and Clarke (2004) submit that "othering" is the act of first naming an individual or group of individuals as different from oneself, and then magnifying those differences to diminish those targeted as the "other" while reinforcing one's own dominant position. For those

treated as the other this act results in “marginalization, decreased opportunities, and exclusion” (Johnson et al, 2004, p.254).

As the physician gained prominence in western society, the medical profession accompanied him (Cascón-Pereira, Kirkpatrick & Exworthy, 2017). To sustain these dominant positions, the act of othering provided a powerful opportunity (Johnson et al, 2004). A particularly effective tool for othering was the concept of *normal* which opened the door for developing processes of isolation rather than connection (Armstrong-Hough, 2015). Wellman (1958) misses the wider repercussions when he raises concerns that use of the word *normal* causes confusion because of its “multiplicity of meanings” (p. 43). Crenner (2014), through his exploration of Julian Herman Lewis’s advocacy, is much closer to the mark when he states that judgment within the scientific laboratory “about normality entailed judgments about human difference” (p. 478). Once the baseline of what was normal was established, then it became easier to categorize what was not normal on the basis of any number of criteria, including (but not exclusively) gender, sexuality, and race.

An example of gender discrimination is how women, under the guise of care and concern for exhibited behaviours such as campaigning for equal rights, were diagnosed as hysterical and forced to stay at home in bed or undergo an oophorectomy, removing not only the ovaries but any chance for children (Briggs, 2000). Ultimately this was a patriarchal response “to the changing roles of women and meanings of gender” (Briggs, 2000, p.249). Sexual preferences that did not fit within narrow concepts of heterosexuality, meanwhile, were pathologized as psychiatric disorders (Bancroft, 2005), leading to hormone treatment for suppression or reorientation therapies (Davidson, 2009). Race, a refutable biological concept (Shih, Bonam, Sanchez & Peck, 2007), nevertheless was utilized as means to produce arguments and actions of

suppression. I have already spoken of the harsh treatment of Indigenous people by western science, barely scratching that surface, while that same scientific approach considered those members of the brown and black races to be deviants (Al-Solaylee, 2016).

The repercussions from this line of thinking in western science and medicine, in all of these categories (gender, sexuality and race), are multiple. One of the most ethically questionable responses, however, is the study of eugenics. This legal-medical approach to social construction sought “biological value and hereditary fitness” (Tanner, 2012, p. 463) through an array of medical procedures to satisfy a drive for “racial hygiene” (Tanner, 2012, p. 468). The most infamous expression of the eugenics movement is the Nazi movement of the mid-twentieth century, but a route to this destination had already been well-marked in many western countries, and some carried this ideology beyond the downfall of the Third Reich (Tanner, 2012). Canada is one such country, invoking policies of sterilization of Indigenous people (Dyck & Lux, 2016) and those considered mentally unfit (Grekul, Krahn, & Odynak, 2004).

I have been using past tense to describe acts of “othering” in order to lay out historical precedent, but it only takes a quick review of a newspaper to confirm the past is very much present. Consider the legion of stories describing how access to health care is restricted or outright denied to queer and transgender people (Logie, James, Tharao, & Loutfy, 2012) and Indigenous people (Gibson, 2015; Leyland, 2016; Rondeau, 2005).

A final note, as it is relevant to the specific subject matter of this thesis, Doyle and Rubinstein’s (2013) study concluded that “othering” through health care staff’s use of “the dementia label in their narratives of the residents often demonstrated the pronounced distance between staff members and residents” (p. 957). Dementia is another category in which

subjugation can take place. I shall explore this matter more deeply in the subsection *Dementia, Traumatic Brain Injury and Responsive Behaviours*.

To summarize, western medicine traditionally favours illness over cause, processes of classification (generalizability and objectiveness), hierarchies of expertise (professionals) and dominance over nature. Upon review, an outstanding question one might have is *where does the patient fit into all of this?*

Patient

Knowing what to call someone who receives care for their health can be challenging as there are numerous definitions for identifying the person, and even more definitions of health. Is health an absence of disease or discomfort in the individual, or an ability to cope daily with life, or a balance of the individual with their environment (Sartorius, 2006)? An Indigenous worldview might define health as a robust interaction with cultural and worldly elements (Parlee, 2005; Tobias & Richmond, 2014), whereas a western approach to health might focus on the cure, the elimination of the disease by separating it from the body (Julliard, Klimenko & Jacob, 2006). Bircher (2005) argues that any definition of health must be dynamic since medicine has become so multifaceted it has developed an identity crisis. This challenge to identity is an apt metaphor when trying to establish nomenclature for one who seeks or requires care.

The debate between the terms “patient” and “client” has been reflective (Ratnapalan, 2009), gently patriarchal (Wing, 1997) and vociferously argued (Neuberger & Tallis, 1999). In long-term care facilities the term “resident” is common (Zuidgeest, Delnoij, Luijkx, de Boer & Westert, 2012). “Survivor” is a catch-all term closely associated with those who have received (and mostly been) treated for cancer (Berry, Davis, Godfrey Flynn, Landercasper, & Deming,

2019). Survivor is a term that Sontag (1989) holds in disdain, connecting it to the complex (and, in her view, damaging) metaphors embedded in the language addressing illness. There is also the term “medical tourist” to identify those who seek out medical treatment in countries or regions not their own, for reasons ranging from cost to treatment availability (Makinde, 2016; Meghani, 2011).

Costa, Mercieca-Bebber, Tesson, Seidler and Lopez (2019) conducted a scoping literature review of preferred terms as stated by those seeking medical attention. The authors acknowledge that “patient” has an etymology that carries with it the problematic implication of “suffering and passivity... characterised by an unequal relationship” (p. 1). In saying that, their conclusions indicate that the overwhelming majority of people choose “patient” as the preferred term of reference. For the purposes of this thesis I will use the term *patient* when referring to someone who requires health support due to a biomedical condition (such as dementia). I do so at the risk of causing confusion because, as will be demonstrated through the video and argued in this thesis, health supports for those with biomedical needs come from health care staff, family and friends. A daughter may not view a parent with dementia as a patient, but I will nevertheless talk about the parent in those terms in order to maintain consistency. I should also mention that this thesis will be arguing that we are all in need of health support at some point, and I hope that clarity can be found by using the term *patient* to specify those that have biomedical needs.

Patient-Centred Care, Person-Centred Care and Narrative

In the last thirty years the medical system has introduced the clinical methodology of patient-centred care in order to mitigate what can be an inherent paternalism (Gluyas, 2015) or even “imperialism” (Bond, Corner, Lilley, & Elwood, 2001, p.316) within health care. Patient-

centred care also challenges the dehumanizing rigour of evidence-based medicine (Stewart et al., 2006, p. 13) which takes an empirical approach to health care (Guyatt et al., 1992; Newton, 2001; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Evidence-based medicine (EBM) and patient-centred care (PCC) have an ongoing and strained partnership in the world of medicine and it is worth taking a few moments to unpack this relationship in order to exemplify the struggles facing the patient-centred approach.

Sur and Philipp (2011) provide a history of EBM, explaining its reliance on scientific methods such as randomized control trials. Clinical decision-making is transformed into disease-based algorithms, and the singular patient is merged into a conglomerate of quantified elements. This harkens back to early medicine's affinity for classification, in which one is part of a population type. Dissenting voices challenge the notion of EBM's primacy. Webb (2018) states that EBM does not value "an individual patient's peculiar context or idiosyncrasies" (p.6), while Ashcroft (2004) expresses concern over how EBM's methodologies lift knowledge away from the domain of the unique and places it into a generalized framework. The vignette "Labels" (time: 11:22—12:57) depicts how a patient is categorized by several health care workers, privileging generic knowledge and excluding the individual.

Patient-centred care responds to EBM's approach by seeking to understand the patient "as a unique human-being" (Balint, 1969, p. 269). PCC seeks to provoke in health workers a relationship-based approach to patient engagement, encouraging them to "walk in kindness, asking questions that matter and being fully present" (Price, Djulbegovic, Biswas & Chatterjee, 2015, p.1050). It is a process that tempers the prioritization of diagnostic knowledge anchoring the philosophy of western medical practice, allowing space for a different kind of relationship (Stewart et al., 2006). Under these circumstances, discussion of disease between a health care

specialist and patient is accompanied by investigation into the *illness experience*, a perspective that embraces the social realities that result from living-with-disease (Toombs, 1993; Skrzypek, 2014). Under the guidance of PCC patients are no longer expected to be passive recipients of information (eg., diagnosis) or practitioners of blind obedience (eg., treatment), but active participants in sharing their stories and discussing and treating their own health (Gluyas, 2015).

Tobin (2018) grapples with the kind of relationship that exists between patient and physician, and how it must be honoured in the sacred form of a covenant:

The relationship between a patient and physician is not a commodity transaction or contract, but a covenant. A covenant is a formal, solemn, and binding agreement, a special kind of promise—like a will or testament. Whereas a contract involves strangers, a covenant is between parties who have a close relationship with each other. Whereas a contract is based on mistrust, a covenant is based on trust. Whereas a contract is between two equal or near-equal parties (each concerned only with its own welfare), a covenant is between two unequal parties - where one is concerned about the welfare of the other. The covenant that patients expect from physicians is “to put a patient’s interests first. (p.1761)

It should be clarified that putting a patient’s interest first does not translate to an absolute deference towards the patient’s wishes. Rather it is the transparent recognition of needs and expectations of all parties through the give and take of dialogue, ultimately achieving, as Stewart et al. state, (2006) a common ground found in a “collective voice” (p. 85). This collective voice can include the many voices of patient, health worker family members and friends (Gill, Leslie, & Marshall, 2016). For an example of this see vignette, “The Grey No” (19:54—20:56).

The benefits of adopting a patient-centred approach are plentiful. Gluyas (2015) identifies “improved outcomes for patients, better use of resources, decreased costs, and increased patient and health care professional satisfaction with care” (p.55). Robinson, Callister, Berry and Dearing (2008) add to the list the ideas of improved communication and “improved adherence” to treatment plans (p. 600).

Patient-centred care is often imagined as concentric circles or as circles within a wheel. There is always a focal point, which is either the label *patient-centred care* or specifically the patient.

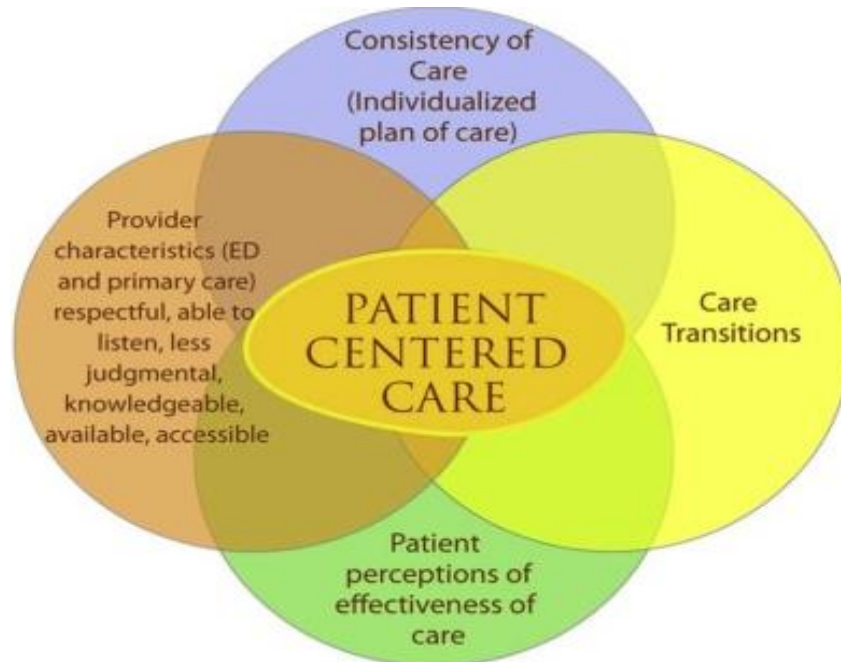


Figure 1. Patient Centred Care concentric circles. Adapted from “Patient-centered care for chronic pain in the emergency department: A qualitative study”, by J. Jambunathan, S. Chappy, J. Siebers and A. Deda, 2016, *International Emergency Nursing* 24, p. 26.

Person-centred care can be viewed as an expansion on the concepts behind patient-centred care, where the scope of consideration has widened to include family members and friends. (Santana et al., 2018). I say “can be” because, as observed by Calisi, Boyko, Vendette and Zagar (2016), many health professionals have “difficulty explaining person-centred care or used patient-centred and person-centred interchangeably” (p. 310). In their own study, however, on general understanding of the meaning behind person-centred care, they included not only health staff and patients but also the patients’ families, providing them a forum to voice their ideas. Hall, Weaver Gravelle and Thibault (2007) studied a person-centred model of care that involved widespread relationship-based collaboration among the health staff to satisfy not only the patient’s needs but also the family’s needs. It is worth noting that their study found that person-centred care increased staff job satisfaction in areas such as collaboration and communication. For an example of this see vignette, “What Makes You Stay” (23:53—25:00).

Brooker, in “Person-Centred Dementia Care” (2007) is one of a handful of literature sources that explicitly connects the term *person-centred* to dementia care (Others include Bellonia, Facciob, Costaa & Iudicib, 2014; Ford, Tesch, Dawborn & Courtney-Pratt, 2018; Kadri et al.). Brooker (2007) still holds onto the paradigm of centralizing the patient while omitting concern for surrounding human supports. She does identify, however, that the “lack of status and value that is attached to people with dementia also extends to those who want to look after their family members with dementia and those whose employment involves caring” (p. 31). Brooker is hinting, however obliquely, at a move towards a panoramic approach to health care. Person-centred care, it can be argued, is care for all people involved in a health-driven context. This consideration includes patients, family members and medical personnel. In the vignette “What

Makes You Stay” (23:53—25:00) the performer/interviewer speaks about care as a “give and take” between everyone.

It would be neglectful to not acknowledge other terminologies in the health care field that closely associate with person-centred care. I offer three others for consideration. *Family-centred care* tends to focus on supporting paediatric patients and their family members (Arabiat, Whitehead, Foster, Shields, & Harris, 2018; Hill, C., Knafl, K., Docherty, S., & Santacroce, S., 2019), recognizing the critical need for a child to have a parent or another loved one in close proximity. *Client-centred care* recommends a “corporate approach” (Schoot, Hirsch, & de Witte, 2007, p. 104) to health care, in which an institution’s resources are coordinated in such a fashion as to maximize the possibility of service. Whalley Hammell (2007) raises an alarm over this philosophy, concerned that organizational concerns may end up taking precedence, actually subverting care for patients. *Relationship-centred care* proposes a reframing of social connections in the health care world into a more vigorous interaction between professional care givers and patients as well as other professional caregivers, honouring a process of knowledge co-creation through collaboration (Hebblethwaite, 2013; Wyer, Silva, Post, & Quinlan, 2014).

No matter what terminology is employed, competence in communication is a key element in developing the kind of relationship that supports health care. Through expanded techniques of information exchange (communication) between patient and physician the larger life-narrative can be gleaned. Buckley, McCormack and Ryan (2018) identify narrative, including patient history and context, as a component in planning care and treatment. In doing so, the health care worker becomes more deeply involved in sustaining the framework of person-centred care. In her book “Narrative Medicine” Charon identifies narrative as “a magnet and a bridge, attracting and uniting diverse fields of human learning” (Charon, 2006, p.11). Narrative

becomes a way to understand illness in Frank's "The Wounded Storyteller." Discussing his own struggles with cancer, Frank (2013) recounts the generation of a narrative, the telling of stories about illness as "the attempt, instigated by the body's disease, to give voice to an experience that medicine cannot describe" (p. 18).

It is useful to differentiate between narrative and story – not an easy task since they are often used interchangeably, much like person- and patient-centred care. Stapleton and Wilson (2017) indicate that certain kinds of stories are "often partial and fragmented, unfold during the course of interaction, are embedded in the interactional context, often focus on the recent past or unfolding events, [and] fulfil social and interpersonal functions" (p. 62). By this definition, one can view stories as reflections of specific events, and as being integral to how we relate to one another in an immediate context. By contrast, Fulford (1999), contemplating narrative's forceful impulses when faced with popular culture's diminutive tendencies notes that narrative can act as a container of thousands of facts arranged into a "meaningful pattern" in order to "draw lessons of human conduct" (p. 30). Narrative, then, is instructive and reflective, less immediate than a story. Bruner (2004) considers narrative through a social constructivist lens, as a reflection of "'possible lives' that are part of one's culture" (p.694). Narrative, then, is characterized through multiplicity. Veland and Lynch (2016) "consider narrative a fundamental human episteme that, through its discourses and scales, provides spatial–temporal coordinates for moving through and manipulating the world" (p.2). Narrative, then, is a systemic way of understanding, providing landmarks for a worldview.

For the purposes of this thesis, I have taken relevant aspects of the various, preceding interpretations and, in my own words, define narrative as *a perception of reality upheld by an underpinning of collected experiences as related through stories*. The stories of the focus groups

were re-formed and assembled into a narrative based on this definition. Narrative is a common element in both person-centred care and playbuilding. Norris (2009) identifies how story—an element of narrative—is critical to the playbuilding methodology. It is for this reason I am approaching my research through the process of playbuilding. I shall speak more on this in the Methodology and Methods chapter.

Dementia, Traumatic Brain Injury and Responsive Behaviours

Communication is one of the key challenges when it comes to caring for people with dementia and traumatic brain injury. Dementia is “an overall term for a set of symptoms that are caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities” (Alzheimer Society of Canada, 2019). Westerhof-Evers, Visser-Keizer, Fasotti and Spikman (2019) describe traumatic brain injury as a condition caused by an external mechanical force striking the head leading to a lesion in the brain. Results from this lesion could include physical and cognitive impairments, and changes to personality and behaviours. Maneewong et al (2017) add that delirium is a common development after a traumatic brain injury. Delirium is “a common clinical syndrome characterized by inattention and acute cognitive dysfunction” (Fong, Tulebaev & Inouye, 2009, p. 210). Communication challenges with an individual living with dementia or a traumatic brain injury impact both kinds of caregivers: professional health workers and friends/family members. Bellonia, Facciob, Costaa, and Iudicib (2014) state that because of communication barriers health workers and patients actually share a common frustration with the situation, a frustration that cannot be resolved in traditional medical paradigms. This assertion is supported by Allwood et al. (2017) who concluded from their study that intuitive practice in verbal and non-verbal exchanges only

serve to disorient patients with dementia. The shared narrative between caregiver and patient is interrupted.

A further difficulty in initiating, building and maintaining a strong caregiver/patient relationship is directly connected to the phenomenon of responsive behaviours, which are defined as “actions, words and gestures... often intentional, that express something important about their personal, social or physical environment” (Alzheimer Society Ontario, 2019). Responsive behaviours include grabbing, cursing, screaming, pacing and crying out for help. Clifford and Doody (2018) argue that health care staff might identify responsive behaviours as part of an illness or personality trait, where other staff, when employing a person-centred care approach might approach responsive behaviours as meaningful, possibly an attempt to communicate. Desai, Wharton, Struble and Blazek (2017) researched and compiled a series of patient-centred strategies that emphasize communication with the patient and patient experience over bio-medical function. Interviewing both informal caregivers (eg., family members) and formal caregivers (eg., health care workers) Herron and Wrathall (2018) conclude that both sets of caregivers struggle with responsive behaviours, leading to frustration and burn-out. They also note that the social, environmental and temporal influences “exacerbated already aggravated” individuals living with dementia (p. 14). Rather than focusing on the dementia and delirium as clinical disorders, caregivers could refer to the definition Belgrave, Allen-Kelsey, Smith, and Flores (2004) provide for Alzheimer’s: “...simultaneously a global way of being and a set or series of day-to-day manifestations... distinctly nonmedical” (p. 207).

Social Justice in Health Care

To bring the literature review to a close, it may be beneficial to cast our gaze through a social justice lens. Sawyer and Norris (2013) define social justice in this way:

The concept of social justice is premised on the recognition of the urgent need to examine power and privilege and improve societal and environmental conditions.

It calls for action to remove personal, institutional, national, and transnational structures that impoverish, disenfranchise, enslave, disempower, and humiliate people. (p.6)

Peñaranda (2015) identifies ongoing disenfranchisement and disempowerment in physician/patient relationships, stating that it is realized through symbolic control. Symbolic control is the regulation and reproduction of power relations through numerous means of communication, such as stories, thus ensuring a domination of one group over another (Lamnias, 2002). Peñaranda (2015) argues that this control is nurtured through assorted forms of education, including that which is provided in the health sector. Guerriero and Correa (2015) argue that an epistemological approach to research and education rather than an ontological approach forces researchers and educators into considering their relationship with subjects and students as non-neutral. If the relationship is non-neutral, then those with knowledge or seeking knowledge must address hierarchical concerns by engaging in empathy and an awareness of subjective discourse. Through an epistemological lens, researchers – all those who seek to generate knowledge and distribute it – become critical scholars who “must pursue, in a direct way, social justice” (Guerriero & Correa, 2015, p. 2635). In other words, through a social justice lens medical educators and researchers can become a lynch pin in altering oppressive approaches and narratives that marginalize patients and communities.

Due to pressure from international organizations and social movements, it is becoming increasingly necessary for institutions, agencies and governments to address marginalization in all social contexts. For example, the United Nations' Convention on the Rights of Persons with Disabilities urges social inclusion for people with disabilities, including equitable access to health care (Committee on the Rights of Persons with Disabilities, 2006). While it is indisputable that equitable access is vital to a fair medical system, health should be viewed as more than access. From a social justice standpoint health is "a framework of defense of human rights" (Peñaranda, 2015, p.991). This could lead to deeper understandings, deeper exchanges between health care workers and patients, and greater sovereignty for patients.

Initiatives within the field of medicine have begun to address such depths. For example, McMaster University and Bethesda Services have engaged in work that exposes emerging health care professionals to the perspectives of people with intellectual and developmental disabilities. "Curriculum of Caring: A Curriculum of Caring for People with Developmental Disabilities" is a website (http://machealth.ca/programs/curriculum_of_caring/) launched in 2015 that provides a platform for those marginalized because of intellectual and developmental disabilities. This website amplifies their personal narratives and challenges the symbolic control referred to by Peñaranda. Boyd, Diepstra, Hamdani and Lunskey (2018) note that medical educators who engage in the narratives of patients "can provide important insights into how to adapt primary care practices" (p.10). Guta, Flicker and Roche, B. (2013) agree that patient inclusion in initiatives such as community-based participatory research has the potential to strengthen the relationships between a health institution (in this case Toronto's Wellesley Institute) and local communities in order to transform health care inequities. They add a cautionary note, however,

that flawed processes can fortify ongoing power differentials, the opposite result of what these programs set out to do.

Adapting and advancing medical practice leads to curriculum development. There is precedent for utilizing patient knowledge and expertise when developing curriculum and assessment. In researching physician compassion training, Sinclair et al (2016) gathered the perspectives of advanced cancer patients in order to identify themes of compassion, gaps in education and approaches for training compassionate care. Coret et al. (2017) demonstrated that persons with intellectual and developmental disabilities can participate extensively in pedagogical process, from the first steps of conceptualizing roles for roleplaying exercises to working as roleplayers (standardized patients) in medical schools. Furthermore, from this study medical students were forced to reassess their notions and reconfigure their narratives on the abilities of people with intellectual and developmental disabilities. Wykurz & Kelly (2002) identified how widespread the harnessing of patient experience was becoming in medical education, and more so, how the work was shifting patient engagement and their accompanying narratives into “a more active role” (p. 818), upsetting pedagogic norms and summoning up the possibility for discomfort to enhance understanding.

Rudy (2014) promotes a pedagogy that advocates for curriculum to be radical and disruptive, pushing liminality within the education system. Mills (1997) defines this pedagogy of disruption as “teaching practices which disrupt marginalising processes by encouraging students to identify and to challenge the assumptions inherent in, and the effects created by, discourses constructing categories of dominance and subservice within contemporary society” (p. 39). Cultural assumptions and dominant paradigms can be put to the test through the use of story, as described by Faulkner and Latham (2013). In their study, teachers first confronted their personal

discomfort by interrogating what stories are permissible to teach and what knowledge might be unsafe for students, and then through a dialogic process the teacher deepened their understanding and began to accept pedagogic risks. This constructivist approach (Xyst, 2019), where knowledge is made through social interaction and relationship-building is the theoretical foundation of the playbuilding methodology and of this study. This brings us to the methodology of this study and the methods employed.

Chapter 3: Methodology and Methods

Methodology

To define research methodology I draw on Porsanger (2004) who identifies it as “a body of approaches and methods, rules and postulates” (p.107). When deciding on a methodology that allowed for the kind of narrative reconfiguration, as seen with Coret et al.’s (2017) research and advocated by Peñaranda (2015), I sought systems that included qualitative designs involving participant voices and experiential learning methods. I looked for a methodology that could provide an empathic response to challenges in the health system and would sustain an intermingling of different knowledge systems to tell a story. The relationship between narrative and theatre-as-activism/research is deeply ingrained, applying “unique mechanisms for the facilitation of humanising encounters” (Rivers, 2015, p. 157). Thus, applied theatre emerged as a practice that provided a large pool of possibilities.

One of applied theatre’s early innovators, Augusto Boal, in the name of addressing oppressive power structures sought to “to stimulate the spectator to transform his society, to engage in revolutionary action” (Boal, 1974/2008, p. 42). Boal invited audience members to step onto the stage (a public space such as a street), and enter the dramatic action where recognition of everyday political and social oppressions would emerge. The audience members - with assistance of a facilitator known as a Joker – would respond to these oppressions, seeking solutions. This process removes the spectator aspect of being audience members, forcing them to sidestep the delegation of power to theatre characters who in traditional theatre contexts “think or [to] act” for them (p.135). The audience becomes active in confronting oppression, rehearsing, as it were, for the real world.

Verbatim theatre carries forth the standard of confronting social oppression by incorporating words from the real world. Starting with the process of interviewing community members, sentences and paragraphs are then lifted directly from the interview transcripts or recordings and placed into a script, ultimately leading to some kind of a performance (Peters, 2017). Paget (2010) argues that because “someone *has said* it adds to the power of these words” (p.185). Criticism for verbatim theatre lies in the very assertion its advocates applaud it, that of authenticity (Anderson & Wilkinson, 2007). If it is replicated, if it is mimetic, then it must be true. This idea of truth runs a close parallel to western medicine’s positivist approach, where there is a search for a single, correct answer. Verbatim theatre’s ties to social justice seem ideal for this work, but in a study that embraces the multiplicity of perspectives that accompany person-centred care, verbatim theatre may be skewed in the wrong direction.

Another use of applied theatre is as a delivery system for disseminating and validating information. Stuttaford et al (2006) describe the Southern Africa Stroke Prevention Initiative (SASPI) research project examining the extent of cardiovascular events and the risk factors in rural African communities. Using the anthropological methodology of rapid ethnographic assessment, data was collected on community beliefs about health, in particular the meaning of and response to one-sided weakness (stroke). In order to validate and disseminate their findings they developed a series of eight critical actions—introduction of characters, hoeing the fields, visiting the clinic, visiting the hospital, going home, visiting the traditional healer, fetching the traditional healer and visiting the prophet—that could be dramatized for an audience of community members. The audience was invited to participate as both performers and decision-makers by arranging the order of the actions. Afterwards, during a debrief, the audience

members vouched for the accuracy the critical actions and engaged in discussion on measures for preventing stroke and other health concerns.

It should be noted that there is a strong history of pairing theatre and health to explore the human side of medicine. The plays *Wit* (Edson, 2001) and *Whose Life is it Anyway?* (Clark, 1974) explore the systemic disenfranchisement of patients. Goldingay, Dieppe, Mangan and Marsden (2014) discuss how forum theatre (Boal, 1974/2008) was employed as a technique to bring to awareness the intricate social interactions that take place between a physician and patient during a consultation. Reader's Theatre (MacRae & Pardue, 2007; Cueva, 2010; Savitt, 2010; Holloway, 2014) is widely used as a pedagogical tool in health care education. In fact, I regularly mounted readings of *Wit* for interprofessional health classes at Niagara College, and later a play, *Now*, that I wrote specifically as a pedagogical tool (Hobbs, 2015). Working on research similar to my study, Kontos et al (2012) developed a play on traumatic brain injury in order to educate health care staff on client-centred care.

Of the possible applied theatre possibilities, playbuilding was the most suitable for this study as it stresses the importance of relationship in its devising process, echoing the fundamental basis of person-centred care.

Playbuilding

Playbuilding is an arts-based research methodology that addresses narratives by devising theatrical vignettes through the collected efforts of individuals (Norris, 2009). It provides a number of advantages in epistemological and axiological areas of study. Epistemologically, playbuilding makes space for a convergence of voices and experience, “a polyphony of perspectives” as stated by Norris (Norris, 2017, p.293). These perspectives when placed side by

side trigger the kinds of questions that look into what we know and how we know it.

Axiologically, through our research we asked ourselves what good health care looks like and what are the pieces that add to those value judgments?

Playbuilding is situated in the realm of constructivism, gathering disparate information to build, revise and rebuild in order to achieve a form of knowledge. According to Phillips (1995) a constructive process is the essence of how humans come to understand the world: as “bodies of public knowledge known as the various disciplines, or the cognitive structures of individual knowers or learners” (p. 5). This is the theory of constructivism. Having many proponents and, thus, theoretical diversity, it becomes necessary to work through the numerous propositions to find the kind of constructivism that best aligns with the work at hand.

John Dewey strongly advocated for experiential activity and social interaction (Phillips, 1995; Dewey, 1938/1997) as criteria in the development of knowledge. Norris (2009) recognizes that Mirror Theatre has a constructivist nature that leads to the pedagogical approach of actively problematizing situations, allowing space for other voices and suggestions, rather than dictating answers (p.124). For an example of playbuilding’s problematizing, see the vignettes, “The Rowdy Bunch” (20:57—22:09) and “Let it Go—Code Lavender” (27:35—28:30). In these vignettes the crystallized, abstract expectations of normalcy—politeness, social graces, appropriate language—is disrupted, creating an opportunity to reconstruct in a pragmatic, creative framework (Garrison, 1998). The process of reconstruction, part of playbuilding’s methodology, involves the questions embedded in the video. The viewer is directly asked to move beyond the role of passive spectator and to begin thinking about a response to the situation. In a live performance Mirror Theatre would use a facilitator or a joker to mediate discussion and perhaps engage audience members alongside performers in actively reconstructing the vignette,

much the way Boal did. A video requires a different approach, however, for facilitating the process of knowledge-making. I will discuss how this might be handled in my conclusion.

Moving beyond theory to examples of praxis, Yoshida (2007) describes how through the use of playbuilding in a Japanese classroom a conversation emerged comparing the textualized western perspectives of Louisa May Alcott's *Little Women* with the personal narratives of Japanese students at a women's college. Small (2007) relates how teaching the French language to students in Jamaica – an act “reinforcing the notion of ‘otherness’, of the difference between big culture and little” (p. 217) - can be turned into a discovery of national narratives through playbuilding activities. These are two examples of how, through the collective effort of seemingly oppositional voices, new narratives are developed. Playbuilding creates a space where dissimilar perspectives are drawn together, and, through devising exercises, are linked through story and placed into dramatic form (Perry, Wessels & Wager, 2013). Norris has asserted “Stories beget stories, and as conversations unfold there is a flood of information as one person's account triggers a flood of information in others” (Norris, 2009, p. 24).

Perry, Wessels and Wager approach their playbuilding work through literacy theory. Their methodology is cyclical. They describe a process that begins reflectively, followed by one form of inquiry (say, observation) then another form of inquiry (say, automatic writing) then further reflection and further forms of inquiry. This is a process of scaffolded learning. Data is gathered from diverse sources in multiple ways in order to achieve an understanding or result that has not been theorized in advance. As a methodology for refuting dominant narratives, the authors argue that playbuilding works “by exposing and exploring particular perspectives or by incorporating a social justice paradigm” (p.656).

Tanner's (2017) playbuilding activities illustrate how ingrained, unconscious elements of white supremacy – defined as the *everyday concept* - can be effectively challenged. Working with twenty high school students, cultural theory and a playbuilding methodology that involved narrative analysis and ethnographic processes, Tanner developed *The Whiteness Project*. In this project, he and the participating high school students engaged Caucasian elementary school students in a variety of exercises (interviews, walks, improvisational workshops) to ascertain their opinions of what whiteness means in the United States. From the resulting responses, the high school students wrote an eighty-two page script “on the circular and repressive nature of Whiteness, through an allegorical telling of a town that suffered from a nondescript virus” (p. 171). The play, presented to approximately eighteen hundred people over six performances was met with tremendous local support, national attention and conservative protests. Tanner discusses how participating students exited the project encouraged and insightful. He also identifies confusion in at least one student. This confusion was not damaging, however. Tanner asserts: “A state of confusion disrupts habit or routine, and requires thinking in order to navigate” (p. 176). In other words, when foundational narratives are disturbed and a new awareness is promoted, deeper learning can initiate.

Such sentiments are echoed by Shapiro and Cho (2011) when they discuss “the disruptive potential of live theater to ‘unbalance’ the audience’s conventional thinking by creating cognitive disequilibrium about sensitive topics, such as race, class, sexual orientation, and gender, that explores their implications for social justice” (p. 351). In their paper “Medical Readers’ Theater: Relevance to Geriatrics Medical Education,” the authors describe a two-year research project that brought together medical students with residents from a nursing home. Over a ninety-minute session the students and residents formed dyads or triads and engaged in theatre games, roleplay

and dramatic script readings. A concluding group debrief invoked discussion on how to provide effective health care to an aging population. Feedback from the medical students praised the project for assisting them in “developing new insights, understanding the perspective of elders, presentation of relevant geriatric issues, and utility and value for future clinical situations” (p. 357). Shapiro and Cho rely heavily on Kolb’s learning theory (Kolb, 1984).

Norris (2016) argues that the act of information gathering is an interaction between researchers, methodologies and the topic, resulting in newly generated content. In other words, only through the ongoing development and reassessment of relationships can knowledge be constructed. He argues this process as a kind of community building, and compares it to the shape of a kite. The beginning point – the chosen topic - is the bottom of the kite, and then the research expands to broadly include generated information and ideas, and finally the research comes together into a single point – knowledge emerges, a performance produced. This understanding of knowledge production resembles Indigenous perspectives of research. Norris, himself makes this connection in his paper “Towards the use of the ‘Great Wheel’” (2011). Objective essentialism (an end-game or conclusive result) is eschewed in favour of continually enhanced awareness through association. Dénomme-Welch and Rowsell (2017) use self-reflexive strategies to examine the close interconnectivity of researchers to subjects, aware that the resulting silences are double-sided. In their view, some silences are erasures of presence while other silences are integral to a learning process where “deeper meanings” are formed through self-reflection (17).

My involvement in this study demanded a regular amount of time being set aside for self-reflection. Many of the reflections are recorded in my log book/ journal (see Appendix B). The March 5th entry muses on my feelings after reading parts of the interview transcript addressing

patient sexual behaviour. I had entered into this project having witnessed my mother in a sexually aggressive state, and through the transcript description I derived a greater understanding of the effect that kind of behaviour can have on others. In the March 12th session I describe how members of Mirror Theatre who read the same transcript (not all of them did) began to relate to one another when sharing transcript information with the larger group. At first they connected with each other through information from the transcript but then they began to share stories and perspectives, building a micro-relationship. It was these tiny, constantly-developing relationships that were critical in our playbuilding process, because they led to knowledge-building and, ultimately, the development of vignettes.

Methods

If a methodology consists of rules, postulates and a theoretical approach for carrying out a study then methods are the array of tools and the implementation of these tools to bring the study to realization (Porsanger, p. 109). Careless and Douglas (2016) outline their set of methods as a process of six boundary markers, while Leavy (2015) argues for a system of methods that leads to a consistency in supporting a methodology.

I systematized my approach, my sequencing of tools, by varying the step-by-step structure outlined by Perry, Wessel and Wager (2013). These steps include *Reflection, Inquiry, Development, Framing, Rehearsal* and *Performance*. Norris (2009) notes, however, that describing a technical, progressive approach to playbuilding inadequately reflects the collaborative efforts of the playbuilding team, and that an interpersonal dimension should be considered when examining the overall process (p. 40). Spirit of play, trust, ownership/co-ownership and performer transformation are some of the elements he argues in favour of

including in research work. As I proceed through this section, I shall touch on all the methods – from inquiry to spirit of play - I used to support story generation, archiving and dissemination of this research.

Story Generation and Devising

To begin discussion on story generation, I shall first introduce my co-researchers: Lindsey Abrams, Dani Shae Barkley, Lindsay Detta, Nadia Ganesh, Bernadette Kahnert, Rosa Moreno, Mike Metz, Abby Rollo, Sumer Seth, Dawson Strangway and Joe Norris. At the time of this study they were all members of Mirror Theatre, many of them for several years. The majority of these individuals were Brock students while one was external to Brock University. A number of the Brock students have recently graduated and moved on, taking with them the experiences from this study and other Mirror Theatre projects.

Norris describes performers in Mirror Theatre as actors/researchers/teachers, or A/R/Tors (Norris, 2009). I used the same term for this research. The primary stipulation to being an A/R/Tor in this study was availability in attending weekly playbuilding sessions for a period of five three-hour sessions. Mirror Theatre's policy is to be flexible, and while some people could not make certain sessions and/or be late or leave early, most attended all of them. There were no stipulations to how an A/R/T identifies in terms of gender, sexuality or ethnicity. I wish to reiterate that the A/R/Tors were not participants but co-researchers. Their sense of play and insight contributed to "a product of human understanding" (Norris, 2009, p. 40) and its dissemination.

I functioned as facilitator and director. Norris (2017) describes this position as D/A/R/Tor (director/actor/researcher/teacher). It was incumbent upon me to lead the group through devising

exercises, to introduce creative prompts, gather and archive the information (stories, ideas) and explain health care concepts when necessary. Most importantly, I needed to ensure and, if need be, further foster a sense of trust. My previous association with Mirror Theatre (at the beginning of the research I had been a member of the company for six months) provided a solid foundation but history does not necessarily guarantee an ongoing sense of trust. Johnstone, Rawson, Hutchinson & Redley (2018) describe how nurses built trust with end-of-life patients by listening to patient stories in order to understand the patient. I, similarly, provided space for the A/R/Tors to explore and share their own responses to the subject matter. Norris (2009) states that being a stakeholder in the research creates a respect for one another's place in the work. All the A/R/Tors are cited in this study as co-authors of the vignettes. In my own preparation for this study I refer to my log book (see Appendix B) to illustrate how I prepared for the first day of rehearsal: "(I) should be part of this questioning process (*what speaks to you or surprises you?*) as it is clear the more I know the less I know. Maybe share this idea with Mirror group." In an effort to situate us all as learners on the same level, exploring together, that is the approach I took.

Playbuilding sessions were located in one of the studio spaces at Brock University's Marilyn I. Walker School of Fine and Performing Arts. The large space allowed for freedom of movement and improvisation, and also ensured privacy.

Our weekly sessions, running from 6 pm to 9 pm, always began in a circle for a check-in and re-acquaintance of each other. Norris, as Artistic Director of Mirror Theatre, had implemented a protocol that involves a talking object, something that is passed from person to person when someone wishes to speak. This ensures that only one person speaks at a time, and that full attention is being given to whoever is speaking (Stevenson, 1999). I included these

talking circle protocols in my sessions for they encouraged “people to tell their stories, construct collective decisions, solve problems, and carry out group processes” (Kurtz, 2013, p.223). I constantly reflected on how hegemony (ie., D/A/R/Tor vs. A/R/Tor) was produced as the sessions unfolded, posing questions to myself. During improvisational exercises were the A/R/Tors looking to me for validation? Did they explore/perform the research differently in my presence? Did I influence their perspectives and work unduly? I observed no difference in performance or interaction from when I was an A/R/Tor in Mirror Theatre as opposed to when I was the D/A/R/Tor in this study. This likely speaks to the professionalism of the company members.

The first session required a contextualization of this study, including how it was part of a larger research project and a clarification of goals. I explained the prime research question: What strategies do health care staff and family members employ when caring for people living with dementia or a traumatic brain injury, and how are these strategies similar or different? I discussed the utilization of a video camera during the improvisations in order to capture the actions and subsequently record them in script form to further our explorations. I let them know that we would inevitably tell some of our own stories that focus on health and ask ourselves a series of questions. What is health? What does it look like when it is good? What does it look like when it is bad?

In this session we then engaged in an icebreaker exercise to focus the group. Appendix B, the log book/journal, describes the exercises for all of the sessions in more detail, and reasons why I chose a particular exercise. The purpose of the icebreaker was to build an ensemble that could attend to the specific needs of this study. On this day I introduced the icebreaker “Wordball”, in which the A/R/Tors had to instantly react to a word given to them (eg., boy) with

their own word (eg., girl). My intention was to draw the A/R/Tors into a mental space where they could respond to the words or statements found in the transcripts without the burden of long-drawn-out contemplation. Each session had its own icebreaker and specific reason as to why it was chosen.

For the remainder of the first session and the two subsequent sessions every A/R/Tor received a photocopy of the focus group transcripts, and by the end every A/R/Tor had read at least two of the five transcripts. At the end of each session the transcripts were returned to a box in a secure office.

It was during the first session, upon the distribution of the transcripts, I introduced the concept of *punctum* to the A/R/Tors. Barthes (2010) investigates the observer's relationship to the visual artefact, the photograph, through the elements of *studium* and *punctum*. He defines *studium* as the generalized interest towards a subject (p. 26). *Punctum*, on the other hand, is the element that is not sought out, but comes at the observer "like an arrow," (p. 26) causing a wound that lasts beyond the act of observation. For each A/R/Tor, the interview transcripts became the *studium*, the subject in this case being the care for people with dementia. A detail in the transcript, an element that resonated with the A/R/Tor and stayed with them as they worked their way through the transcripts, was the *punctum*. A *punctum* might have been a single word or a phrase or a concept that for whatever reason was glaring and lingered.

To illustrate, the phrase "grey no" was identified by several A/R/Tors as something memorable that emerged from their reading. Other examples included transcript quotes such as "code Lavender" and "did I make the right decision", or approaches to communication such as the use of baby talk and open-ended questions, or potential vignette titles such as "Finding the

Time” and “What to Pack”. Of note, “What to Pack” later became the vignette title “Packing Memories”. All of the A/R/Tor responses can be viewed in Appendix A, “Transcript Responses”.

Beyond the reading of the transcripts we also engaged in the dialogic process of group discussion. The A/R/Tors expressed verbally their responses to the transcripts, leading to thoughts and questions about health care and dementia. More insights, more puncta materialized.

Each punctum was recorded on a recipe card. The A/R/Tors included their initials and the transcript name and any other supporting information they thought relevant. I created a five-column spreadsheet and copied the information from these cards. One column was for transcript quotes, one was for responses/puncta, and the other columns were for the A/R/Tor’s name, transcript name and transcript page number. There were one hundred and eighty-six rows of either puncta or transcript quotes. A sample of the spreadsheet is found in Appendix A. I also developed a colour coding system to identify potential titles, themes and scenes. Once completed, I showed the A/R/Tors the spreadsheet so that we could discuss approaches and subjects that seemed important to include in our series of vignettes.

Throughout this process we were devising vignettes development. Over the five sessions (not including the day we videotaped the vignettes) we devised numerous short scenes. Throughout these sessions we explored a subset of three questions as framed by Hughes, Whyte and Norris:

1. What are the current practices that support and/or resist person-centred care approaches from the perspective of patients, family members and staff?

2. What are the conditions that support and/or challenge person-centred care? How do stakeholders negotiate identified challenges?

3. *What are the personal and professional tensions of practicing person-centred care?*

It became apparent that the concept of person-centred care was foreign to many of the A/R/Tors. In the third session I provided specific definitions of person-centred care, and discussed examples. This stimulated a vibrant discussion as the A/R/Tors connected these concepts to their own experiences. In order to avoid swaying the A/R/Tors toward perspectives they might not hold, I waited until most of the transcript reading had been completed to discuss external perspectives of person-centred care.

As mentioned a few pages earlier, I systematized my approach to the playbuilding process. These steps included *Reflection*, *Inquiry*, *Development*, *Framing*, *Rehearsal* and *Performance*.

The A/R/Tors began the process with *Reflection*. In the first sessions when we were reading the transcripts I asked them to write down on recipe cards as many descriptive, single-word responses as possible. These cards were kept in a folder for future reference. The words became compass points, not considered as fixed data, but prompts for story development. The purpose of reflection was to engage the A/R/Tors in a style of automatic writing (Bacopoulos-Viau, 2019) where the unconscious became part of knowledge-construction, and the A/R/Tors' responses to the transcripts were unfiltered. Reflection was an exploration of the A/R/Tors' own perspectives and attitudes towards health.

Inquiry was the second step. Based on the established descriptors and images we began improvising scenes. People separated into groups of two or more. Much of this work falls in the realm of embodiment. It is the instant that an idea or thought presents itself, and through an imaginative act the performer allows the thought to inhabit the body and present itself in physical

form (Blair, 2010). After the devising process each group presented its scene to the rest of the company and then there was discussion on its meaning. This was a process I likened to narrative analysis. The cohort A/R/Tors sometimes asked about the absence of details and the reason behind the absence, or consideration was given on why more weight was placed on one aspect of the vignette and less on another aspect. Through this dialogue, over a period of time, themes began to emerge. These themes were recorded for future reference. The steps of Inquiry and Reflection were repeated several times as the cohort delved deeper into the meaning of the stories and meaning behind the stories. This was a spiral process, turning like an auger as we sought to answer our questions.

Throughout the process of improvisation (and later, rehearsal) the vignettes were captured by cell phone video recordings for reference. We uploaded the videos onto a private Facebook page. Only members of Mirror Theatre could access this page and these videos. In this way, if an A/R/Tor wanted to remind herself or himself of the vignette they had worked on the week before, they could do so.

Alternately, at the end of a session some A/R/Tors wrote a general outline of the scene they helped devise. Since we were not writing formal scripts it necessary to record the work we had completed after each session.

After the initial improvisations had taken place, the A/R/Tors entered into the *Development* stage. This is when deeper improvisation of the vignettes occurred. The improvisation involved the construction of monologues and action sequences based on the stories that emerged from Reflection and Inquiry, allowing for a rough narrative to take shape.

Meanings behind scenes became more complex as more words and actions were added into the storytelling.

Once a body of knowledge was constructed, the next step was *Framing*. This step involved taking the vignettes and arranging them within a narrative context. This was not vignette sequencing, which was a process that occurred later during the editing of the video by Brad, Joe and myself. As a group we reviewed what we had accomplished so far, asking ourselves what themes and critical stories were addressed and what voices from the transcripts were audible, and what was missing. For example, I had a concern that not enough of the family perspective was represented, and so we devised two more scenes to fill the gap.

Rehearsal was also knowledge-construction. During this step a dramatic verisimilitude was discovered. Motivations of characters that theoretically worked were adjusted to suit a practical presentation. Language that initially sounded correct was reworked. As D/A/R/Tor I asked myself if the collection of vignettes honoured those the sociocultural and political contexts we discovered in the transcripts. By now the vignettes had been named in order to track which vignette was which. Consistency in naming was crucial. We discovered, on occasion, that people referred to different scenes with different names resulting in confusion, slowing down our rehearsal process.

Each vignette developed in its own, unique way. The scene known as “Packing Memories” (time: 3:40—6:48) has a presentation style reminiscent of theatrical naturalism (Zola, 1986; Jacobus, 1989) providing the viewer with a slice of life and detailed minutiae without dramatic flourish. In it a brother and sister are packing a suitcase for their mother who has just entered a nursing home. They are negotiating what items are necessary to bring. Some clothes

are packed and some are left behind. The relevance of a stuffed flamingo is debated. A brief discussion on how old photographs have therapeutic value takes place. The siblings' attitude towards the future is enhanced by their encounters with objects from the past. This is a vignette that represents relationships on a variety of levels: through familial and temporal, as well as through physical artifacts. The seed of this vignette is found in the transcript response on line 29 (see Appendix A) about "decorating mom's room".

Metaphor

Metaphor is a device that relays specific information from a precise reality into a more universal format. Looking at it another way, it allows an action to migrate to different contexts rather than anchoring it to a single time and place, yet still maintains links between the contexts (Livingston, 1991). In the vignette called "Turntable Etiquette" (time: 1:14—1:55) metaphor is most prominently utilized. Four performers cluster back-to-back, and then rotate as a group as if they were standing on a record turntable, stopping when one of the performers faces the camera. The camera becomes the stand-in for a patient, and the audience of the video adopts the point-of-view (POV) of the patient (Kawin, 1987, p. 73). I shall speak more on video point-of-view in the upcoming section on editing. Once the performer is facing the camera they make a verbal acknowledgement. This acknowledgment could be in the form of a greeting, or more darkly as a shrouded accusation that might involve soiling one's pants. After the statement is delivered the group rotates so that another performer can have their turn addressing the camera/patient. The statements become increasingly derogatory, infantilizing the patient. A clicking sound effect made off-camera by a ratchet adds to the illusion that this vignette is portraying a machine in action.

The combination of movement, sound effect and scripted statements metaphorically indicate the automated approach to staff/patient communication that can take place in health care institutions. This vignette was based on numerous responses to the transcripts, such as “understanding the patient's perspective” (see Appendix A, line 20), “how people are approached” (see Appendix A, line 49) and “I can wipe your bum bum. How are we today.” (see Appendix A, line 82). Not wanting to limit ourselves to a single setting or moment in time because of those multiple responses, the use of metaphor seemed to be the best way to represent the transcripts. Provenzo, Mccloskey, Kottkamp and Cohn (1989) note that metaphor “allows the understanding an individual already possesses to contribute to the interpretation of experience for which present understanding and descriptions are inadequate” (p.554). Faulkner (2009) adds that metaphor also helps organize those experiences (p. 91). The machine metaphor is intended to disrupt the status quo by lifting language into prominence, thus opening up discussion on how and why automated communication can take place in any context.

Shadow Screen

An indispensable element in our video shoot was the shadow screen. It was in sixteen of the twenty-one vignettes. It was approximately six feet in width and four feet in height, made taller when placed on a two-foot stand. When a light (an overhead projector in our case) was shone behind the screen anyone who stood between the light and the screen cast a silhouette. Dark figures were visible to the eye, as were their actions, but when it came to discerning the features of the individual it was difficult to tell unless one was well-acquainted with the performer. Often another performer would stand in front of the screen, features fully visible, and interact with the silhouette. Mirror Theatre had frequently made use of the shadow screen when presenting vignettes, either live or on video (Norris, 2009).

The shadow screen served numerous purposes. It solved the problem of representation, it provided emotional safety, it allowed for an engagement of Brecht's alienation effect, and it acted as a metaphor.

With regards to *representation*, we had a demographics quandary. The majority of A/R/Tors in Mirror Theatre were in their twenties. Only a few members were close to the age where dementia from a disease such as Alzheimer's was likely. Traumatic Brain Injury (TBI) is a possibility at any age, but the majority of scenes would have involved a patient with TBI and that approach would have ignored the majority of stories in the focus group transcripts. Furthermore, representation in research (Smith, 2012; Wilson, 2008) and in art (Fei and Sun, 2006; Johnson-Cunningham, 2018) is tricky and can easily misrepresent, generating and/or perpetuating negative reflections and outright damage on communities. Our solution was to establish the convention that anyone portraying a patient would be placed behind the screen, creating a barrier that allowed for interpretation. Knapp (1964) argues that the viewer will attribute characteristics based on other forms of stimuli which, in our vignettes, would be principally the verbal cues of the script. On a final note, it was family members and health care staff who had taken part in the focus groups, not the patients. Providing greater visibility to those who had voiced the stories seemed to be a more ethical approach to this devising process. Thus, scenes like "Communication on Bath Day" (9:27—11:20) and "Tic Toc" (13:26—15:55) not only had performers in their twenties playing patients with dementia in silhouette, but the performers representing staff were in front of the screen, clearly visible.

It is that same barrier that provided a sense of *emotional safety* for the A/R/Tors. In the vignette "The Rowdy Bunch" (time: 20:57—22:09) four of the male performers provided a number of misogynistic slurs toward the female nurse who was reminiscing about an event that

took place in a patient's room. The A/R/Tors acknowledged discomfort in speaking the dialogue, though all agreed that it was important to express these attitudes in language that was not watered-down. The screen allowed the performers to distance themselves much the way Lecoq saw the physical mask liberating performers to explore the grotesque (Cogent, 2016). Norris (2009) has also used the shadow screen for protective purposes, realizing the vulnerability of performers when dealing with body image in the Mirror Theatre show *Cattle Call* (p. 138).

Through the *alienation effect* (Brecht, 1961; Bai, 1998) of the screen the spectator is free to step away from the theatrical aesthetic and character identification (Norris, 2009) that can immerse and lull a viewer. Brecht argues for the “unfamiliar world” in order to quash the spectator's habitual need for distraction by seeking an onstage surrogate (Brecht, 1996, p. 82). The shadow screen creates both a familiar and an unfamiliar world, a paradox, in which an interval of questioning by the spectator is centrally placed in the flow of suspended disbelief. As demonstrated in a number of scenes, for example “Let it Go—Code Lavender” (time: 27:35—28:30) the juxtaposed conversation between a clearly visible performer and a silhouetted performer creates a cognitive and visual disconnect. The viewer is stimulated to think about the scene rather than responding to the vignette with emotion. In the three Interview vignettes (“Family Interviews”, time: 2:25—3:10; “Staff Interviews”, time: 17:45—18:19; “What Makes You Stay?”, time: 23:53—25:00) the silhouettes mimic the voice-overs delivered by other performers off-screen. This provides a disjointed experience for the viewer. Similarly, all of the A/R/Tors wore their Mirror Theatre shirts and played multiple roles; we did this in order to produce and sustain the alienation effect.

Lastly, the screen became a *metaphor* of the dark and light states of being in the long-term care facilities, as stated in the focus group transcripts and subsequently devised as themes in

the vignettes. There is despair and hope, disgust and joy, entrapment and relief. The use of shadow conveys familiar, binary oppositions (Kawin, 1987). Franklin (1980) notes that shadow, when visualized on film, also becomes a mirror, reflecting metaphorically the characters onscreen. The silhouettes in the vignettes may represent patients but they also act as echoes of the staff ("We are all just human beings"; see Appendix A, line 43) or loved ones ("If this was my mom or dad, would I want others to treat them?" see Appendix A, line 161). Elsaesser and Hagener (2015) move outside of the dramatized playing area and consider the intimacy between the spectator and the screen, where the empathic response transfers the viewer into the space that is being viewed. The shadow screen does not only hold shadows and light, it holds us.

External Sources

During the process of devising scenes the majority of the work was based on responses to transcripts and the A/R/Tors' own experiences. There were, however, times when we looked to external sources to clarify questions or to help focus a scene. For example, most Mirror Theatre performers were unfamiliar with the concept of person-centred care. In session two I provided a definition from a literature source which then led into a discussion of different concepts of health care. (see Appendix B, session two).

In the scene "Should It Be Normal?" (time: 22:10—23:41) we were looking for a way to address concerns found in the transcripts about physical abuses committed by patients. Some of the responses to the transcripts (see Appendix A) include "What point does it become too much for staff to handle?" (line 70), "When do we take them out of restraints..." (line 150) and "How do you respect the dignity of someone when they don't respect yours?" (line 179). The devising generated scenes that were far too didactic for such a physical topic. In my external research I

came across Brophy, Keith and Hurley's paper "Breaking Point: Violence against Long-Term Care Staff" (2019). They described their research survey method of "body-mapping", in which long-term care workers marked on a paper outline of a human body where on their body physical or sexual violence had taken place. The diagram provided by the authors triggered in me the idea to use the shadow silhouette and laser pointers to indicate where on the body an assault might take place. I used the silhouetted image of Da Vinci's Vitruvian Man (Murtinho, 2015), believing that the familiarity of the image alongside the concept of the ideal body would uncomfortably juxtapose with the systemically flawed acceptance of violence as normal. While not strictly speaking Image Theatre (Boal, 1974/2008; Grant, 2017), this approach to physical and sexual assault follows through on the paradigm that a visual cue can often provoke far more powerful responses than verbal descriptions.

Videoing

Performance was the final stage. This is both the dissemination of the data generated as well as a further mediation of that data. As expressed by Valle and Connor (2012) it is through performance that further discoveries are made by "infinite intrapersonal connections" (p. 19) between audience member and performer. Norris (2009) concurs, emphasizing that the research processes of collection, analysis and dissemination can be simultaneous. In this thesis, performance is realized through videotaping. We videotaped all of the vignettes on a single nine-hour period, and during this day we developed two new vignettes and continued to hone those we had already devised. The videographer was Brad McDonald, a frequent collaborator with Mirror Theatre. He set up three video cameras and numerous lights, transforming a Brock rehearsal space at the Marilyn I Walker into a film studio.

To keep the day on track and efficient, I created a shooting schedule. (see Appendix C). I arranged for all of the vignettes that involved the shadow screen to be videoed first. The screen takes approximately 15 minutes to set up and it was easier to construct it at the beginning of the day before the camera had been set up.

Included in the schedule was the order of the vignettes, their names, which A/R/Tor was in each vignette, props and costume required and the kind of shot that would be required (eg., wide, medium). While one vignette was being videoed, the A/R/Tors in the next vignette were preparing. Since Brad, our videographer, had only seen a few of the vignettes in advance through the Facebook page, I provided him with a sense of the action, describing content and the playing space that would have to be videoed. He made appropriate adjustments to the lighting and camera angles while the A/R/Tors rehearsed, and then we shot the scene. There were usually two or three takes per vignette, supplying us with a significant amount of footage for the editing.

By the end of the day we had videotaped 21 vignettes.

Sequencing for Editing

The editing process involved Brad McDonald, Joe Norris and me. Brad operated as the technician, working with the editing program to make the necessary adjustments. He also provided creative input, acting as a third eye when necessary. Joe and I were the principal editors. We agreed upon a system in which I would take the initial steps in the editing process and he would respond with suggestions for change. Since the final video would fulfill the obligation of Mirror Theatre's part in the research project, and since Joe Norris is the Artistic Director of Mirror Theatre, it was necessary for Joe to take on duties that satisfied his

responsibility as a thesis supervisor, and also allowed him sufficient oversight as an artistic director and research co-applicant for the larger study.

Approximately three weeks after the video shoot Brad created a rough cut of each vignette. This became our starting point for the editing process. I grappled with the challenge of arranging the vignettes in a sequence that would form a narrative. Would the narrative adhere to a temporal sequencing (ie., hero-patient arrives and travels through the health care system), or a cohort sequencing (ie., arrange vignettes so there is first a focus on the family perspective and then on staff perspective), or a thematic sequencing (ie., create clusters of patient centred principles). My working definition of narrative for this study was: a perception of reality upheld by an underpinning of collected experiences as related through stories. Any one of the above sequences could potentially work. I took a closer look at the content in the vignettes.

The vignettes devised by Mirror Theatre were based on the punctum responses of the A/R/Tors. As a result the vignettes as a whole were relevant to concepts of person-centred care in a long-term care facility, but story-wise they were independent of each other. They lacked a thread that could be developed into a single plot-based storyline. In other words, the narrative could not reflect a hero's journey through a passage of time. Nor did it seem appropriate or even possible to divide the vignettes into family perspectives and staff perspectives. Too many of the vignettes contained the perspectives of both. Furthermore, separating the voices seemed to run counter to the concept of person-centred care as an inclusive approach to health.

I was left with a thematic approach to the narrative. I considered some of the critical principles of person-centred care and looked for patterns (Harris, 2016, p. 34) within the videoed vignettes that included those elements. I found that the principles of communication,

collaboration, recognition of needs/empathy and job satisfaction were well-represented. As a result, I clustered the vignettes into thematic versions of these principles, knowing that every cluster of vignettes would share principles with other clusters. In collaboration with Joe I turned these clusters into chapters for the video. The chapters were named: “The Loooooong Goodbye”, “Let’s Talk...”, “Time”, “Understanding Another’s Perspective” and “How Do You Cope?”. You will find in Appendix D the worksheet used for making notes on editing, including how I thematically clustered and sequenced the vignettes. For reference purposes, I have provided the row numbers in the worksheet for each chapter.

The opening chapter has no name since it immediately follows the video title; its sequence of vignettes and questions from rows 5-8 consider the person-centred principle of *communication*. The chapter titled “The Loooooong Goodbye” (rows 9-11) illustrates *recognition of needs/empathy*, with particular focus on the family. The chapter titled “Let’s Talk...” (rows 12-16) deals with *collaboration*. “Time” (rows 17-21) is the chapter that tackles both *communication* and *collaboration*. The chapter, “Understanding Another’s Perspective” (rows 22-29), also addresses the principle of *recognition of needs/empathy*, but in this case the focus is on the health care staff. We introduce the chapter with a question and vignette of staff interviews before officially entering into the chapter. The final chapter is called “How Do You Cope?” (rows 30-35) and it considers the principle of *job satisfaction*.

In the process of editing one of the vignettes was cut, leaving us with twenty. This vignette provided information about the number of years of health care providers were on the job, repeating information from another vignette, “Staff Interviews” (time: 17:45—18:19). By removing this vignette we lost a scene that listed the various disciplines within an urban health sciences centre. It was a loss that seemed acceptable considering that the viewers of the video

would be primarily health care staff, and an accounting of departmental supports did not seem relevant. As Harris (2016) says, the primary questions in a video research study should be “*Who is your audience?*” and “*How will you reach them?*” (p. 103). The audience for this video does not need to hear about the kinds of disciplines involved in dementia care.

I will now take a few moments to discuss two film techniques employed in this video: point-of-view and transition. Other techniques can be found in the video but I am concentrating on these two because of their ability to disrupt the spectator.

Point-of-View

The screen, where images from film and video come into being, is a threshold that connects two worlds—the world of the spectator and the world represented by film/video (Elsaesser and Hagener, 2015, p. 40). The framing and action within that represented world can provide distance for the spectator, relieving them of moral obligations to intervene or take action (p. 15). The comfort of the spectator can be transgressed, however, by a direct, intrusive look from the performer into the camera, as if dismantling the threshold in order to catch the spectator in a moment of unauthorized viewing (Kawin, p. 73). The spectator is no longer passive, no longer free of responsibility. The spectator is involved in the narration.

It was this potential for inclusivity that the vignette “Turntable Etiquette” (time: 1:14—1:55) was chosen as the opening vignette. The intention was to draw whatever audience member who was viewing the video into the conversation as quickly as possible. This technique was used two other times, in the vignette “What if I Called It Earlier?” (time: 16:38—17:18) and in “Mis(sed)understanding” (time: 18:32—19:53). Both of these vignettes present staff members who are in a moment of crisis (physical assault, angry family member “haunting” the memory)

and who are unable to talk to anyone about their sense of guilt. In this case, the spectator is no longer an intruder but a confidant.

It's should be mentioned that point-of-view can have a negative impact if executed improperly. In the vignette "Let it Go Pen Click" the A/R/Tor accidentally makes eye contact with the camera twice (see (25:04 and 25:13). This shatters the illusion of the scene, and there is no pedagogical value in doing so. At that moment in the scene nothing needs to be emphasized in order to make a point or to situate the viewer as a different kind of spectator.

Dissolve

The dissolve was chosen in certain scenes to transition between two sets of sequences within a vignette. The visual strength of the dissolve comes from the melting of one image into another image (Kawin, p. 223), each one embodying the other's essence briefly, making explicit a connection between the images or sequences.

The vignette "Tic Toc" (time: 13:26—15:55) uses the dissolve several times. This vignette was intended to represent how in an unpredictable work environment time is not a constant, and that it fluctuates in speed (faster, slower, stop) and even direction (forward versus backward). The action within the vignette would not be sufficient to indicate to the viewer a variation in time. We required the presence of a clock. One of our A/R/Tors, Lindsey, took on the task of depicting an analogue clock by moving her arms and making ticking noises; we called her the Lindsey-clock. In the editing it was important to juxtapose time and action. When we videoed the scene one camera captured Lindsey-clock's movements while the other two cameras recorded the other A/R/Tors. I had initially mused about placing the image of Lindsey-clock into the top corner of the main vignette, reminiscent of a count-down timer. I dismissed the idea since

the Lindsey-clock image would have been too small and could be ignored by the viewer. I wanted to ensure time was forefront, particularly since the title of the vignette was “Tic Toc”, so the dissolve was used. Within two minutes and thirty-two seconds the Lindsey-clock appeared seven times. The frequency of the clock’s appearance in juxtaposition with the action of the scene created tension.

The tic toc sound of the clock (generated by Lindsey’ clicking tongue) is an important addition to the vignette. The clock sounds are both diegetic and non-diegetic (Elsaesser and Hagener, 2015, p. 154), occurring within the scene as the sounds of a ticking clock might, while remaining separate. The everyday sounds of a timepiece are metaphoric (Ondaatje, 2002, p. 125), indicating chaos while overseeing the action and commenting on it. When Lindsey expresses, “ding, dong, ding, dong”, she does so at the closure of action sequences (such as nurse/patient argument leading to the flipping of a tray) as if to highlight the severity of the moment.

Chapter 4: Transcript

Early in this thesis you may have viewed the video and while I discussed in written format the literature review, methodology and theory you were able to make visual connections, finding relationships through different forms of knowledge. For the most part I have moved past discussing theory, etc. and now it seems appropriate to provide the transcript. I will still provide video reference points but you also might find it useful to refer to the transcript as it is an active piece in the mediation of this study.

I wish to make a point on the placement of the transcript. I deliberately did not include the transcript as an appendix. Like every other chapter in the thesis the transcript is part of a

pedagogical process that is still active, still finding relationships. In this decision I utilize Donmoyer and Yennie-Donmoyer (1995), in which they discovered during their research into reader's theatre, "the processes of data analysis and readers theater script construction were really not very different from each other" (p. 409). This transcript is story mediation (or data analysis, in other terms) and needs to be housed within the body of the thesis. It may also be prudent to consider Chun and Plass (1997) who advocate different presentation modes of information to facilitate understanding and satisfy two information storage systems: verbal (symbolic representations such as words in text) and non-verbal (visual representations such as video pictures). The more recent literature from Toraldo, Islam and Mangia (2018) differentiates text-based knowledge from the more "tacit, aesthetic, and embodied" (p. 440) elusive forms of knowledge in video without negating the value of either. With this in mind, I contend both video and text should be part of the thesis body as active mobilizers of knowledge, and neither should be relegated to the appendices.

Scene List

	Scene Title
1	Turntable Etiquette
2	Family Interview
3	Packing Memories
4	Breakfast Offerings
5	Communication on Bath Day
6	Labels
7	Tick Tock
8	Meant to Tell You/Code Lavender

9	What if I Called it Earlier?
10	Staff Interviews
11	Mis(sed) Understanding
12	The Grey No
13	The Rowdy Bunch
14	Should It Be Normal?
15	What Males You Stay?
16	Let It Go: Annoying Behaviour
17	Let It Go: Ray of Sunshine
18	Let It Go: Code Lavender
19	Let It Go: Monologue
20	Thank You

Understanding Person-Centred Care: Finding Dignity Within the Shadows

Transcription Notes:

- *vignettes are not identified in video by name but are identified in transcript to differentiate scenes*
- *staff members are numerically identified as Health Worker 1 (HW1), Health Worker 2 (HW2) etc. Each vignette resets the numeral which means that although most vignettes have a HW1, HW2 and so on, these are to be understood as different Health Workers.*
- *For the most part, patients and family members are identified by name. No patient or family member is in more than one vignette*

- *The following A/R/Tors are co-researchers and co-authors: Lindsey Abrams, Dani Shae Barkley, Lindsay Detta, Nadia Ganesh, Bernadette Kahnert, Rosa Moreno, Mike Metz, Abby Rollo, Sumer Seth, Dawson Strangway and Joe Norris*

INTRODUCTION VOICE OVER (V.O.):

This is not your typical instructional video. We show many challenging, complex situations without sugar-coating. The purpose of this video is to assist families and health care providers in understanding each other's experiences and perspectives. Only then can we start a dialogue about person-centred care and the ways we might work through those naturally messy situations.

You are about to see numerous theatrical vignettes, created in response to focus group transcripts. The performers play multiple parts. This means in one vignette someone might represent a family member and in next vignette they might be portraying a nurse.

Throughout we will leave you questions to ponder, and hope you will have many more of your own. Feel free to stop at any point to think and discuss, or save your thoughts until the very end.

Vignette: TURNTABLE ETIQUETTE

1. Welcome to our facility.
2. Oh, so you're back in my unit, hey?
3. Hi how's it going today?
4. Well hello there.
1. Oh, did you make this big mess?
2. Does someone miss their family?
3. Aww someone made a boo boo!

4. Would you like a snack?

QUESTION V.O.

First impressions linger. How would you respond to the addresses in the last vignette? How would you respond if you were a family member or patient? How would you change the form of acknowledgement if you were a staff member?

STATEMENT V.O.

Patients coming to long-term care facilities have a series of hellos and goodbyes. We interviewed staff and family members to get a sense of these interpersonal relationships. Here is some of what we found.

Vignette: FAMILY INTERVIEWS

Interviewer: so we would like to know your experiences as family members of residents in long-term care. We will be taking your stories to dramatize them.

1. As a family member I believe you've got to treat a person as a total individual. And tone of voice is huge.
2. And no baby talk.
3. And here's another one for you. So my dad shares a room with two other gents. They share the same bathroom. My dad wears dentures but the other two gentlemen do not. And I walk in one day and the other gentleman was accusing my dad of taking his toothbrush, and my dad's saying, 'What the hell are you talking about? I didn't take your toothbrush.' And the other guy's saying, 'You bloody well did.' And my dad says, 'I wear dentures. I don't need your toothbrush.' So the other guy just wasn't quite

understanding and I went over to the guy and I said, ‘Look, his dentures are like stars.

They come out at night. And he has no need of your toothbrush.’ So I think humour can diffuse a whole lot of stuff.

Title Card: THE LOOOOOOOOOOOOONG GOODBYE

Vignette: PACKING MEMORIES

Brother: Okay sis. What else do we want to pack for mom?

Sister: Well we already have all of her clothes sorted. So I guess its sorting through everything in this room.

B: Okay, well, let’s think about what’s practical. What does she need? Like, does she need another jacket?

S; I’m not sure. She went there in one.

B: Mmmhmm.

S: Maybe just pack it anyways?

B: Yeah just in case.

S: Yeah.

B: Okay, what else?

S: I don’t know. I don’t know where to start. Like what is this? We’re not New York fans.

B: You don’t remember our trip to New York?

S: I don't think so. I was pretty little.

B: Dad bought this. And I think mom just kept it.

S: That's really sweet.

B: Think I'll keep this one.

S: I think you should. Well, packing this little guy's a no-brainer.

B: Umm. Why?

S: It's one of her favourites.

B: But does she need it?

S: I think she needs it. I mean, she's always petting it and hugging it. It's actually really sweet.

B: She's not a child.

S: I know she's not a child. But that doesn't mean that something like this doesn't mean something to her.

B: Okay. Pack it.

S: Oh. I knew these were around here. The photo albums.

B: Maybe not.

S: Why not?

B: Well, I mean, she's not going to be able to remember most of these things.

S: Well, she's not going to remember unless we remind her. Remember what they said. They said that we need to bring pictures. That way she can try and remember.

B: But if she can't remember she'll just get frustrated.

S: So you're just gonna want her to forget everything?

B: I don't know. Okay, maybe just... maybe just one.

S: Okay.

B: Why did she even keep all of this stuff?

S: I don't know. This was her life. These are all her memories. I didn't even know mom drew.

B: She didn't. That's mine.

S: Here you go.

B: I don't even remember the last time I drew.

S: Maybe you can start again.

B: Maybe.

S: This is a lot of stuff.

B: Yeah.

S: We're going to have to say goodbye to a lot of it, aren't we?

B: Yeah.

S: I really didn't think it was going to be this hard.

QUESTION V.O.

Whenever a new patient arrives, everyone's world changes. How did yours or how might yours change?

Title card: LET'S TALK

QUESTION V.O.

How could communication structures be improved between family and staff? And staff among themselves? What have you experienced?

Vignette: BREAKFAST OFFERINGS

Healthcare worker 1: Breakfast time and I do have your food. So will you please at least try it?

Resident: No

HW1: But it looks really quite good and I think you'll enjoy it.

R: No.

HW1: Could you please just calm down –

R: No!

Healthcare Worker 2: Good morning Joe. Are you hungry this morning?

R: No.

HW2: No? Um, would you like me to leave it here and maybe you can decide when you're hungry and eat it on your own time?

R: [shrugs. Non-verbal response]

Son: Hey dad. How are they treating you?

R: [shrugs. Non-verbal response]

Son: That looks pretty good is that your lunch? It's a little early for lunch. Or is that breakfast. Have you not eaten breakfast?

R: No.

Son: Just haven't eaten it?

R: No.

Son: Hm. Uh nurse. Could you explain to me why my dad hasn't eaten his breakfast.

HW2: Well, we did bring his breakfast in a couple of times but he didn't seem like he wanted it so we left it here for him. And, ah, for him to eat it on his own time.

Son: On his own time?

HW2: Yeah.

Son: So you're just letting my dad go without food. Ah, when was the last time he ate?

HW2: He ate last night.

Son: Last night.

HW2: Yes.

Son: And you didn't think it was important for him to eat this morning?

HW2: No, of course not. We - I just felt if I hovered over him and watched him eat he'd feel uncomfortable and, uh, so I left it here so he can eat on his own time.

Son: Well, maybe if you did your job better you would find a different tactic to get him to eat his food.

HW2: Well, I'm sorry if I've upset you. Maybe we can, ah, come together and talk about ways that we can get your father to eat and maybe he can join us as well and get his opinion on what he would prefer.

Son: Yeah. Let's talk.

Vignette: COMMUNICATION ON BATH DAY

Health Worker 1: Good morning Mr. Jones. I see on my chart here that it's your bath day today. Um, would you be willing to take a bath?

Resident: No. No.

HW1: Now Mr. Jones. It, it has been about six days now. I'm just worried about your health. It's time for you to take a bath.

R: No.

HW1: Come with me. It's right down the hall. It won't be, it won't be that far.

R: No.

HW1: Alright Mr. Jones. I'll be back.

Son: [on phone] Hello.

HW1: [on phone] Hello. This is the nurse at the long-term care facility. Uh, who am I speaking to?

Son: This is Derek Jones.

HW1: Oh. Hi Derek. I'm just calling about your father.

Son: Oh, is everything alright?

HW1: Yes. He hasn't washed in about six days. Um. And he's refusing to take a bath, a bath today.

Son: Oh. That's unlike him. He usually washed pretty regularly. Wait wait. Did you say, did you say bath?

HW1: Uh, yes.

Son: That might be part of the problem. My dad never took baths. He only had a shower in his home. So I don't know if that had something to do with it or not.

HW1: Oh. Oh, okay. Perhaps I'll try asking him about that then.

Son: Okay. Well let me know how it goes.

HW1: Yes I will. Thank you.

Son: Thanks. Bye bye.

HW1: Mr. Jones? Now I know it's not your regular bath time. Um, but I was wondering. Would you like to take a bath or a shower?

R: [shakes head. Non-verbal] Uhh. No.

HW1: Well would you be willing to take a shower?

R: [nods head. Non-verbal] Yes.

Vignette: LABELS

Health Worker 1: [writes in chart] Patient is difficult.

Health Worker 2: [reads in chart] Difficult. [speaks to camera/patient] So are you going to be difficult today? [writes in chart] Patient refuses to have breakfast.

Health Worker 3: [reads in chart] Okay. Hmm. [speaks to camera/patient] So we're going to work on eating breakfast. [writes in chart] Patient lashes out.

Health Worker 4: [reads chart then speaks to camera/patient] Hi Mr. Hobbs. How are you doing today? Oh you didn't like that? Well I can bring you a different meal next time. Okay, I'm going to check in on you later, alright? [writes in chart] Patient is having a difficult time adjusting to the new environment, due to dietary restrictions, change of the meals...

Responds well to positive feedback.

Title Card: TIME

Question: Time can move forward, backwards and sometimes it stands still. When do you live in the present, when do you live in the past, when do you live in the future? Are you aware of when other people live with a different clock than yours?

The following vignettes consider time in different contexts.

Vignette: TIC TOC

Clock (represented by actor) is making ticking noises and moving arms as a clock might.

Health Worker 1: Good morning Mrs. Johnston. You're looking quite well today.

Mrs. Johnston: Thank you Bernadette.

HW1: Um. Doesn't look like you've had much of your breakfast. Did you not like it?

M.J.: I don't want any.

HW1: Would you like me to take it away?

M.J. Yes.

HW1: Alright. I'll do that. And I will be back to check on you shortly.

M.J.: Thank you.

HW1: No problem.

Clock arms move and pause with the sound "ding dong ding dong". Then arms speed up.

HW1: *[meeting other health worker]* Mrs. Johnston didn't eat any of her breakfast. I have other patients. Could you possibly see if you can get her to eat something?

Health Care Worker 2: Yes. Of course.

HW2: Of course.

HW1: Thank you so much.

Clock arms pause with the sound “ding dong ding dong”. Then arms continue at slower speed.

HW2: *[speaking with MJ]* Hello Mrs. Johnstone. We’ve brought your breakfast back so hopefully you can eat some.

M.J.: You’re not Bernadette.

HW2: No I’m not Bernadette. I’m Lindsay.

M.J.: That’s not mine.

HW2: Yes. This is your breakfast. It’s got your name on it.

M.J.: No. That, that isn’t mine.

HW2: Oh yes.

M.J.: I don’t want it.

HW2: Are you sure? Look at that maple syrup. It looks so good.

M.J.: I want to see the doctor.

HW2: Okay. No problem. Why don’t you have a few bites?

M.J.: No. I don’t want any,

HW2: And then if you have a few bites then I’ll bring the doctor

M.J.: I don’t want any. I don’t want any! *[knocks tray of food into HW2]*

Clock sounds “ding dong ding dong”. Tic toc speeds up.

HW1: *[meeting HW2]* Hey, how are you? Oh?

HW2: Yeah. I didn't go very good. Can you watch for me? I gotta get cleaned up.

HW1: Oh of course. Take care of yourself.

Clock sounds "ding dong ding dong". Tic Toc slows down.

HW1: *[speaking with MJ]* Hello Mrs. Johnstone.

M.J.: Bernadette.

HW1: I heard there was a bit of an incident at breakfast. *[picks up photo]* Oh what's this?

Oh, this is such a lovely picture. Could you tell me about it?

M.J.: Oh yes. That's my wedding in 1951. And that's my husband Charlie. And my sister there. She played the piano for the wedding. Um, and I had such a lovely bouquet. And doesn't Charlie look handsome in his new suit?

HW1: Oh he does.

M.J.: Oh I can still smell the flowers. April lilies.

Clock arms are moving backwards. Ticking has slowed down.

HW1: That's such a lovely memory, Mrs. Johnstone. Do you need anything before I go?

M.J.: Um, Bernadette?

HW1: Yes?

M.J.: Where is Charlie?

Clock arms and ticking both stop.

Vignette: MEANT TO TELL YOU/CODE LAVENDER

Health Worker 1: Hey there Dani Shae – What happened to your eye?

Health Worker 2: Oh, well... it's not a big deal. But yesterday when I was helping Joe, um I was bringing in his breakfast, and, um when I walked in I saw that, well, that he was punching himself in the face. Um, and so when I reached in to grab his arm he... he hit me.

HW1: Yeahhh. Um. I forgot to tell you that when you grab his hands he tends to get aggressive.

HW2: Oh. I wished they had given us more time to debrief.

Vignette: WHAT IF I CALLED IT EARLIER?

Health Worker 1: So, one day I went to check in on a patient. *[to silhouette of patient Mr. Seth]* Hi Mr. Seth. How are you doing today?

M.S.: No! Go! No please! Get them away!

HW1: Mr. Seth. Everything's alright. You're in a hospital.

M.S.: Who are you?

HW1: *[to camera]* I mean, clearly he was in distress. *[to patient]* Mr. Seth., everything's alright here. I'm a nurse. I'm just here to check and see how you're doing.

M.S.: Please, please! Just get John. I don't want to be here! Where am I?

HW1: I didn't really know what to do. I panicked. And my colleague Lindsay heard the commotion from the hallway.

M.S.: Who are you? Who! Who! No!

HW1: Things were escalating.

M.S.: Get away! Go, go! Leave me alone!

HW1: And suddenly, out of nowhere, she got hit.

M.S. hits silhouette of Lindsay.

HW1: I had to run and call a code white. The only thing going on in my mind now is: should I have called it earlier?

Statement: Staff told us in the focus groups about their ongoing commitment to achieve “therapeutic rapport” and to understand what the patients are going through.

Vignette: STAFF INTERVIEWS

Interviewer: So we would like to know your experiences as staff in acute long-term care. We'll take your stories and dramatize them. So, how long have you been staff here?

Health Worker 1: I've been here officially three years.

Health Worker 2: Fourteen years.

Health Worker 3: Z wing, for twenty-two years.

Interviewer: Wow.

Health Worker 4: Fifteen

Health Worker 5: Eighteen and a half.

All: *Laughter*

Interviewer: So clearly when you come here you stay.

All: *Laughter, "yeah"*

Health Worker 6: Well, I have been here for twenty-four years.

All: *Laughter*

Title Card: UNDERSTANDING ANOTHER'S PERSPECTIVE

Question: So much goes on behind the scenes that others may not know about. What's new for you? What stories might you add?

Vignette: MIS(SED)UNDERSTANDING

Health Worker 1: Okay Mr. Jones, time to go to the Remembrance Day ceremony.

Mr. Jones: No.

HW1: You don't want to go to the Remembrance Day ceremony?

M.J.: Too many bad memories.

Son: Uh, excuse me. Why wasn't my father brought to the Remembrance Day ceremony? I mean he's a veteran. He had every right to be there. He really should have been brought.

HW1: He said he didn't want to go. *[turns to Mr. Jones]* Okay, Mr. Jones. Let's put on that music.

Son: Um, sorry. Is that Mozart? My dad would never listen to Mozart.

HW1: He seems to like it now.

Son: Hmm. And what's going on with his food? I mean, everything's mixed together. He never ate like that he always kept the peas separate from the carrots. That's how we always ate.

HW1: Well, when he came here he seemed to mush it all together.

Son: Well... at least tell me when is he going to see the physiotherapist? I need to know when he's going to be able to walk again.

HW1: *[to camera]* I never had time to adequately talk to Mr. Jones' family. Uhh, they took him to another institution before we had the opportunity to talk things through. We never had a time to reconcile. Or to bring things to closure. I still think I could have done something differently. I'm still haunted by it.

Vignette: THE GREY NO

Health Worker 1: Hello Mr. Lee. I have your medication.

Mr. Lee: I said I don't want it.

HW1: *[to Health Worker 2]* This is Mr. Lee's medication. He's been refusing for, like, the past three hours.

Health Worker 2: Let's just add it to his applesauce. Oh, let me show you.

HW1: Okay.

HW2: *[brings in supplies]* Hold this. *[mixes medication with applesauce]* Here you go.

HW1: But he did say no to it.

HW2: That's just a grey no.

HW1: What's a grey no?

Joe: So our family signed a power of attorney. And what we said was if my father was going to cause harm to himself or someone else you have the right to give medication. In all other circumstances – no.

Vignette: THE ROWDY BUNCH

Health Worker 1: Hey Abby.

Health Worker 2: Hey sweetheart. How are you?

HW1: I'm okay. But I was actually wondering if I could talk to you for a minute.

HW2: Yeah, I can make time.

HW1: So, I was visiting this patient in the TBI ward. *[silhouette of four figures appears]* And there were these four male visitors and they were being pretty rowdy.

All Rowdy: *Laughing. Garbled comments.*

HW1: So I told them: hey guys, I'm sorry to interrupt but there's only allowed to be two visitors per room. But if you guys would like to continue talking you can go down to the café. And then they said...

Rowdy 1: Yeah, Yeah, we'll move downstairs. Why don't you join us, huh sweetheart?

Rowdy 2: Yeah, you can sit on all of our laps.

Rowdy 3: That's a great deal. Four for the price of one coffee.

Rowdy 1: Woo!

Rowdy 4: And some sugar.

HW1: So... I just kinda stood there. I didn't know what to do. And then after a while I just walked away and slammed the door.

Door slam and silhouette light goes out.

All Rowdy: Bitch!

Vignette: SHOULD IT BE NORMAL?

Mr. Seth: Nurse. Hi there you are.

Health Worker 1: Oh Mr. Seth, how are you?

M.S.: I'm good, I'm good. How are you?

HW1: I'm good. I'm just grabbing some coffee.

M.S.: That's awesome. Um. I just came by to apologize for last week. My dad pulled your hair.

Silhouette appears. Vitruvian Man

HW1: Oh, it's fine. Don't worry about it.

M.S.: Okay. How's your head, by the way?

HW1: It's just a bit sore but it'll be fine in a couple of days.

Red, laser pointer dot on silhouette head.

M.S.: That's good. That's good. How is he otherwise? Is everything okay?

HW1: You know he's much better. In the past he used to be very aggressive when we would try to transfer him from his bed to his wheelchair.

M.S.: Yeah.

HW1: He would elbow us in the stomach, in the chest, and the arm, and sometimes even in the face. *[red dots on stomach, chest, arms and head]* But now we know to let him try to do it on his own. And if he does need help we'll step in.

M.S.: Yeah. That usually works. I know he can get a little physical sometimes. And that's usually when he wants attention. So he'll start grabbing and everything.

HW1: Yeah.

M.S.: My body is evidence of that.

HW1: I'm so sorry.

M.S.: It's okay.

HW1: Yeah.

M.S.: Yeah. Umm, oh. And the... groping.

HW1: I mean he used to do that a lot in the past.

M.S.: Yeah, I'm just asking. Because he did it to me and, yeah, I'm his son so...

HW1: Yeah. I'm sorry. You know, but, it's happened in the past but you know it's, it's happened so much it's just become normal.

M.S.: Should it even be normal?

Red dots all over the silhouette.

HW1: I... I don't know when it started being normal. And, should it stop being normal?

Title Card: HOW DO YOU COPE?

Question: We all have ways of coping. If we don't care for ourselves, then how do we care for another?

Vignette: WHAT MAKES YOU STAY?

Interviewer 1: So what makes you stay?

HW1: It's appreciation.

HW2: Like, someone says, 'I'm so happy my loved one is here. I'm glad my dad is somewhere safe.'

HW3: Or when you're at a family conference and you just receive a thank you.

HW4: And someone offering to buy you lunch at the deli.

Interviewer 2: Really?

HW4: Well I graciously refused. It was the thought that counts.

HW5: Ultimately it's where the rubber meets the road. Not just medically, but other ways as well.

Interviewer 1: And so, part of your joy is when the person comes back after rehab and says, 'Thank you. I don't remember a lot but thank you.' And all of a sudden all that stuff, it makes sense. That's why you come back to your jobs.

Interviewer 2: I completely agree with you. That's where the starting part is. For me, caring is mutual. It's a give and take, it's a back and forth among everyone. That's the idea.

Vignette: LET IT GO—ANNOYING BEHAVIOUR

Silhouette of patient, Joe, clicking pen.

Health Worker Lindsay: *[note: this is the only example of a health worker continuing through a series of vignettes]* Back to your clicking, hey? Are you doing Morse code over there? What are you trying to tell me? Don't you have anything else to play with? Alright we'll see you tomorrow.

Meets Health Worker 2

HWL: Hi.

HW2: Oh hey. How are you today?

HWL: Yeah, I'm okay. You know, Joe. He's back to his clicking.

HW2: His clicking?

HWL: Clicking of the pen.

HW2: Oh. Does that bother you?

HWL: Yeah. It's super annoying. Don't you agree?

HW2: I've kinda learned to let it go.

HWL: Yeah, I guess I should do that too.

Vignette: LET IT GO—RAY OF SUNSHINE

HWL: Well, good morning Kevin. How are you today?

Kevin: Oh, I'm good now that you're here.

HWL: Oh yeah?

Kevin: Yeah. You're such a ray of sunshine. I love to see your smile.

HWL: Oh. Why thank you.

Kevin: Yeah.

HWL: That's very kind.

Kevin: Yeah, yeah.

HWL: Who's this ray of sunshine you've got here?

Kevin: Oh. Oh, that's just an old friend of mine.

HWL: Oh yeah? You keep her awfully close to your bed.

Kevin: Oh. Do you remember... when we used to dance outside? You used to put on the record. And we swayed in the moonlight. And sometimes we swayed under the stars. Do you remember that?

HWL: Are you sure it wasn't this fine lady in the photo?

Kevin: No, no. I'm sure it was you.

HWL: Oh.

Kevin: We just held each other tight. The waves just splashed around us. It was really nice.

HWL: Okay. I'm going to be back in just a few moments, okay?

HWL meets with brother.

Brother: Hi sis. How was work?

HWL: Yeah, it was quite the day.

Brother: Oh Yeah?

HWL: Yeah. I had this interesting fellow today. He thought I was a ray of sunshine. Yeah, very interesting. Then I think, like, he thought I was his wife. Like he was having an episode.

Brother: Oh.

HWL: It was just a bit of a sticky situation.

Brother: Yeah, sounds pretty tough.

HWL: But you know what? On my way home, just laugh it all off. Because at the end of the day I do just gotta let it go.

Brother: Yeah, that's all you can do, right?

HWL: Yeah.

Vignette: LET IT GO —CODE LAVENDER

HWL: Good morning Joe. I've got your breakfast. We're going to change your bandages on your head later this afternoon.

Joe: Okay that's very good. Very kind of you.

HWL: How are you doing today?

Joe: Not too bad. Are you married?

HWL: Uh, no. I'm not married.

Joe: You're not married. Any kids?

HWL: No. No kids. No.

Joe: Oh. Okay, what about, uh, siblings? Brothers and sisters?

HWL: Yes. You know what. I have one brother and one sister.

Joe: And do you live alone or do you live with them?

HWL: We all live together.

Joe: You do? That's really good to know. Because when I get out of here, one night I'm going to sneak into your house. And I'm going to tie you up. And I'm going to tie your brother and sister up. And I'm going to have you watch me torture them! I'm gonna-

HWL: I'm just going to leave that there, okay. We'll see you later.

HWL meets with Health Worker 3.

HWL: Do you have time for a code lavender?

Vignette: LET IT GO—MONOLOGUE

HWL: This is a daily reality. And you step aside and you think: you know what, I have twelve hours with this patient. And then you come back and you do another twelve hour shift again. But in the end you just sort of... keep on going.

Statement: Even in the shadows, dignity can be found. In what ways have you been treated with dignity? And how have you respected the dignity of others?

Vignette: THANK YOU

Conversation A

Health Worker 1: It's a tough day, today. So, why do we do this? Like, why do we keep coming back?

Health Worker 2: It's rewarding. Sometimes it's a little smile on your face, perhaps a laugh. It just makes you feel good.

Health Worker 3: Like that one young man who left three months ago. He's recovering but he's teaching other people about his journey. And his family is forever grateful. They think that we did great work with them. Um, and they thank us eternally for just getting him to where he is. That's one story.

Conversation B

Health Worker 4: When you look at them as a person, you're seeing them as a person. Getting to know them, who they are, where they come from.

Health Worker 5: A lot of our patients when they come to us, they've spent, like, weeks to months in the ICU. And then all of sudden they're on our ward and we get to help them these firsts of, hey, for the first time I can.

HW4: It seems silly. They get to go to the toilet for the first time. Or they get to wash their hair and have someone braid it. Or they get to brush their teeth today.

Conversation C

Health Worker 6: I mean it's the little wins, right? You really start to notice the little wins.

Health Worker 7: Mmhm. You know, it's lovely when a family member of a veteran offers to buy you something from the deli. Even when you say no, they insist.

HW6: Mmhm. And I think the best part is watching a veteran come in, really ill, and then eventually being well enough to participate in something again.

HW7: Yeah.

HW6: It's amazing.

Conversation A

HW1: So I've been at the end-stage dementia unit for seven years now. And you know sometimes you won't see progress or so obvious in someone as you might see in someone who is mentally more healthy.

HW2: And sometimes it's just the little things. Like a tap on your hand or a tap to the music. It's a change in behaviour that's more positive than prior.

HW3: Sometimes –

All: When they just say thank you.

END CREDITS

Mirror Theatre Presents

“Understanding Person Centred Care: Finding Dignity in the Shadows”

Directed by Kevin Hobbs

Written and Performed by Mirror Theatre's Cast

Lindsey Abrams

Dani Shae Barkley

Lindsay Detta

Nadia Ganesh

Bernadette Kahnert

Rosa Moreno

Mike Metz

Joe Norris

Abby Rollo

Sumer Seth

Dawson Strangway

Narrated by

Kevin Hobbs

Filmed by

Brad McDonald

Edited by

Brad McDonald

Kevin Hobbs

Joe Norris

Supported by

The 2011 Social Sciences and Humanities Research Council (SSHRC) Insight Development

Grant for: Reuniting Form and Content Generating, Mediating & Disseminating Social

Science Research & Arts-based Performance Genres Through Digital Media

Sunnybrook 2017 Practice Based Research and Innovation Seed Grant Program

Department of Dramatic Arts, Brock University

Chapter 5: Conclusion

Transcript Reflections

As I draw this thesis to a close I wish to present a few of the vignettes in order to circle back to the concepts behind person-centred care in order to make explicit some connections between it and the transcript. Incidentally, it has been odd calling chapter four a *transcript*. Technically, because I (a spectator) transcribed what was verbalized on the video, the document is a transcript. Yet, I (a co-creator) was also involved in the development of the scenes before the videoing took place, and this form of pre-planning is a kind of scripting. Brownlow (2000) relates how the transcription of his interview with the film director Lewis Milestone was rewritten by Milestone, who condensed interview scenes and added dialogue. Milestone created a script, providing another perspective not obtained during the original interview. The final Brownlow/Milestone article was both transcript and script. The transcript you read in this thesis seems to be a similar thing, although the process with the members of Mirror Theatre was much more collaborative. Perhaps chapter four should be titled *(Trans)script*, emphasizing the transitional or mutable nature of this work. For now, it's best to move on.

I have chosen three vignettes from the video. Each scene is divided into *content* and *form*. I will consider how, through both content and form, aspects of person-centred care emerge, ready for discussion.

Breakfast offerings. 7:14-9:24

Content.

This vignette shows a sequence of events in which a patient refuses to eat his breakfast despite the efforts of two staff workers. The patient's son enters the scene, realizes his father hasn't eaten breakfast and criticizes the staff. The vignette demonstrates the perseverance required when caring for patients with dementia or TBI, and in particular the different *communication* styles as exemplified by the two different workers.

Also present is the thesis/antithesis of the perceptions of *the ideal versus the real*. In an ideal situation the patient would have eaten his breakfast when it was first delivered. It would be ideal because there was less effort and concern for the patient's nourishment would have been relieved. The reality that took shape (for whatever reason) left a breakfast tray untouched, two staff members occupied with feeding the patient, a frustrated patient and an angry son berating staff for a perceived failure on their part.

Form.

This is a *realistic* scene, with a beginning, middle and an end. The video is populated with vignettes that take different presentational forms in order to ensure ongoing engagement with the viewer. If the twenty vignettes were all realistic or all metaphorical the audience member would quickly lose interest.

The final words in the vignette come from the son who says, "Let's talk." These are the same words on the previously viewed title card, emphasizing this section in the video as one that tackles communication. The son's agreement to talk lifts the scene from individualization into a *metanarrative*.

Mis(sed) understanding. 18:32-19:53

Content.

This vignette begins with a patient refusing a staff worker's offer to go to a Remembrance Day ceremony. From that point a family member enters the scene demanding why his father did not go to the ceremony, and then launches into a litany of complaints, indicating dissatisfaction over his father's care. We are exploring the theme of *expectation*. The staff worker expects the patient, a war veteran, to want to attend a Remembrance Day ceremony. The son has similar expectations, but also presumes the father would not appreciate the music of Mozart and the mixing of his vegetables. Both the staff worker and the son have placed the resident into an identity bin based on past circumstances (eg., proud veteran, picky eater). In the world of person-centred care flexibility is required as individuals—particularly those with dementia and TBI—shift their needs and desires.

The role of *interpreter* is prominent in this vignette. While the staff member may have been mistaken about the ceremony, he was very clear on the patient's other preferences. The staff member has, in effect, become the interpreter of the patient's wishes. The son, still lost in the temporal zone of who his father once was, imbuing the present with the past, is unwilling to accept the intermediary position the staff member now holds. Unable to understand or hear the staff member, the son removes his father from the long-term care facility without resolving the conflict.

Form.

The *placement* (or blocking, in theatre terms) of the three A/R/Tors in the scene was deliberate. The staff member was positioned between the patient and the son, forcing him to turn from one to another in a kind of balancing act. Visually, this creates tension as the staff worker

appears trapped. To heighten the effect we developed the scene so that the patient and the son never acknowledge each other; they are polar opposites unable to connect in order to resolve the untenable situation.

In an act of desperation the staff member breaks the relatively realistic discourse in the scene by turning toward the camera and directly addressing the viewer: “I never had time to adequately talk to Mr. Jones’ family”. In the background, the son has frozen. We as the viewer see the participants in the conflict but know that in this case we cannot do anything to help.

Should it be normal? 22:10-23:41

Content.

This is the scene in which a family member and a staff worker discuss the responsive behaviours of the patient, behaviours that are both violent and sexually aggressive. The subject of violence in a long-term care facility problematizes the concept of person-centred care, which is based on reciprocal actions that allow for *dignity*. It is critical to acknowledge that both staff and family members struggle when caring for someone who may no longer understand the concept of socially appropriate behaviour or may have a different interpretation due to their cognitive state.

In a way, this scene is a fantasy scene. While not an impossible scenario the likelihood of a staff member and a family member discussing so frankly the kinds of assaults they have experienced are unusual (Majerovitz, Mollott, & Rudder, 2009). The set-up for this event, however, allows for the possibility of *self-reflection* in the form of a series of questions: “Should it even be normal?” “I don’t know when it started being normal.” “And, should it stop being

normal?” Providing the viewer an example of a self-reflective moment underscores the need for this practice within a person-centred context (Niessen, & Jacobs, 2015).

Form.

The image of the Vitruvian Man, when transformed into a silhouette becomes representative of all people. Gender is put aside as is relational identity (family member, staff member), for anyone is *vulnerable* to assault when caring for someone with dementia or TBI. Again, using the shadow screen, we problematize person-centred care in the context of violence.

The laser points on the silhouette are a crucial element to this scene. Harkening back to western medicine’s fixation on Descartes, we present an image of the body’s ontology as a pixilation of disease points. Under the umbrella of that philosophy the experiences of the patient were important only as a guide for the physician to reach the disease. We undercut this approach to health care by placing those who have experienced harm front and centre, allowing them the opportunity to *share their narratives*.

Next Steps

Knowing more stories, finding deeper relationships

Divergent and contradictory perspectives on health care emerged from both the focus group transcripts and the A/R/Tor responses. From the transcripts it was clear these incongruencies were not simply polarities between groups, but also within groups. Often health care staff could not agree upon approaches to achieve person-centred care. The same can be said about family members. Add into the mix social expectations and systemic processes and it becomes obvious the complexities of a person-centred approach can only be addressed through

research methodologies that embrace the ambiguous, the contradictory and the uncomfortable. Wolgemuth and Donohue (2006) advocate for a narrative approach which is well-suited to exploring the intricacies of contradictory stories. Playbuilding can further the inquiry by juxtaposing those contradictions in order to problematize and create dialogue, potentially leading to an experience of transformation.

There is more that can be done to realize the transformation. As stated in the introductory chapter, attending or not attending to relationship emerged as a critical component in how successful a health interaction might be. Relationships are key.

In their study on the impact of theatrical representations of social issues, Byrne, Elliot and Williams (2016) argue that involving marginalized populations in the creation of a drama presentation about themselves “can make new understandings of community contexts and futures possible, reinstating forms of utopian thinking, in which communities themselves are involved in the authorship” (p.730). The co-production of a new narrative based on old narratives may help to heal where healing is necessary, and renovate fixed views into fresh possibilities. I speak about seeking the stories, but ultimately this research is about the thoughts evoked and the dialogue that emerges in a community.

This transformative process, this winding path from the hidden, individual experiences of health care staff, people living with dementia or a traumatic brain injury, and their family members to a more open, shared, community experience will be a step in a more inclusive direction in person-centred care. The Truth and Reconciliation Commission (2015) notes that stories are healing medicines, and that the arts “invite people to explore their own worldviews, values, beliefs, and attitudes that may be barriers to healing, justice, and reconciliation” (p.178).

The stories of person-centred care, uncovered and shared by the A/R/Tors through this playbuilding research, could benefit staff, family and patients at health centres, and beyond.

Two future workshops

As a next step to assist in satisfying research question four in the larger study, “how can video vignettes enable patients, family members and staff to advance the principles of person-centred care?”, Norris, Hughes, Whyte and Hobbs have created a first draft of two workshops as part of this study’s continuum. As well, Norris and Whyte have applied for a Social Science and Humanities Research Grant in order to continue the partnership with Sunnybrook Health Sciences Centre in the delivery of these workshops.

Workshop #1: Perspectives in person-centred care

This workshop will be two hours, presenting the video and a live performance of some of the vignettes. A facilitator (Norris and/or Hobbs) will have an opportunity to transform the audience from the passive role of spectator into active participant. Through the intervention of a facilitator the audience might provide suggestions or actively participate in the reshuffling and reconstructing of vignettes to better understand the “concepts of power and reconciliation” (Norris, 2009, p. 81). The design of the participatory workshop is intended to stimulate discussion on current practices that support or resist person-centred care in acute care facilities, and to inspire performance-based inquiry into alternate approaches to achieving this care. Rather than utilizing a didactic pedagogy to educate learners in person-centred care, these workshops will encourage dialogue and co-creation of new forms of knowledge. Conquergood (2002) notes that a performance-based workshop is “grounded in active, intimate, hands-on participation and personal connection” (p. 146).

In a live performance of this set of vignettes Mirror Theatre would be able to transform the audience from the passive role of spectator into active participant. Through the intervention of a Joker, the audience might provide suggestions or actively participate in the reshuffling and reconstructing of vignettes to better understand the “concepts of power and reconciliation” (Norris, 2009, p. 81). This is a relationship that comes from being part of a live performance. When it comes to a video presentation the possibilities of engagement change. Boal’s Joker cannot summon the “magical reality” (Boal, 1974/2008, p. 159) where onstage representation can be adjusted.

Workshop #2: Developing Facilitators

This workshop will be four hours, and will include A/R/Tors, members of Sunnybrook’s health care staff and other qualified persons who may have interest in developing a facilitation skill-set. They will have been required to have observed at least two previous participatory workshops and will be taken through a series of exercises that focus on listening, interpreting and questioning. This will promote a dialogic approach of shared authority. As identified in an earlier chapter, questions have been placed in the video to prompt the spectator into a mode of inquiry. The questions themselves may not encourage a spontaneous dialogic process, and assistance may be required. Without such assistance, Österlind’s (2008) insights on embedded social patterns, that “there are always several alternatives and that not one of these is right” (p. 75), and Mackey’s (2016) impulse to create space for a multiple voices could be lost.

If further mediation in this process is required, Linds (2008) offers a solution in the form of facilitation. A skilled facilitator can integrate “purposes, processes and outcomes” (p. 102), guiding viewers of the video past what might be surface responses towards a meaningful reflection of their own practice and/or relationship to others (Poekert, 2011, p.35). Vettraino, Linds and Goulet, L. (2013) have this to say about facilitation:

The teacher or facilitator brings structure to and establishes constraints on activities, but these constraints need to be ones that allow for a diversity of response, creating a space between rigid structures and “anything goes.” Shared authority emerges which is “a beginning, not a destination—and the beginning of a necessarily complex, demanding process of social and self-discovery. (p. 200).

Facilitation under these circumstances is a relationship based on dialogic processes, and through shared authority a constructivist approach to knowledge-building can be produced with the assistance of a facilitator. There is a level of skill that makes a good facilitator, and Linds emphasizes ethics as a critical component in how facilitators conduct themselves. Not everyone can facilitate.

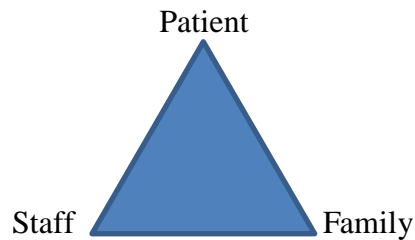
Defining Person-Centred Care

Further study into how person-centred care and patient-centred care differ is worth exploring. I submit that an approach advocating for broad consideration of all people involved in the illness experience could be a next step in possible research avenues, adding to the literature—and more importantly, the practice—of health care.

In the final vignette, “Thank you” one of the staff talks about how a recovering patient is “teaching other people about his journey” (time: 29:00—30:51). This line in the devised script

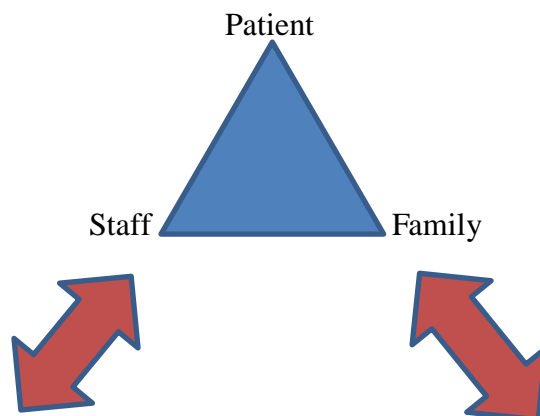
echoes a number of quotes from the transcripts, including a health worker's statement on a number of her patients: "I have room for veterans who are teachers - they teach me how to age" (see Appendix A, row 85). If, as suggested by another interviewee in the transcript, "we're all on the same journey" (see Appendix A, row 58) then how might this be envisioned?

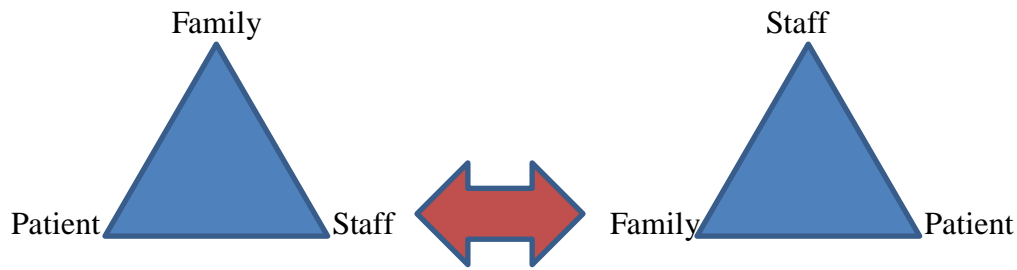
Rather than a circle of care in which the patient always sits in the centre, surrounded by staff and family, perhaps it might be worth reimagining the circle into a triangle of care, where patients, family and friends and health staff each have a point of intersection where they receive some kind of support.



The difficulty with a triadic pattern is that while it allows for three foci points, it still can appear to privilege hierarchical standings because someone's got to be at the top. Perhaps, as we did in "Turntable Etiquette" there is an opportunity to rotate through, to take turns in giving and receiving the care, thereby honouring the concept of relational accountability.

Below is a diagram theorizing how this might happen.





A Personal Summary

This research has, in many ways, been a rewarding experience. It has also been difficult. Three weeks into the Social Justice and Equity Master's program, on September 28, 2017, my mother passed away. She was living with Alzheimer's, and had been in a nursing home for eight years. I and my two siblings were with her for the final four days of her life. Although I am remembering this now, I do not speak strictly from a space of recollection. I was finishing the assigned reading for my theory course, Sara Ahmed's *Willful Subjects* (2014), throughout that time. It was inevitable that I would compare Ahmed's theories on the willful labours of the body to the oppositional forces within my mother's own body, where the lungs frequently seized while her heart beat unhesitatingly. She was a strong woman with a powerful will. My father died on May 5, 2019, symbolically book-ending my studies. He had dementia, the result of Parkinson's disease, and passed away in the same nursing home, just four rooms down the hall from where my mother lived and died. Once again, we three children sat with him over his final days, all of us experiencing what can be described in an opaque and murky space. None of us regretted being in that space.

Some of the thesis writing took place during the last days of my father's life, and a few days following his death. The day after he died I found myself carrying out the reverse scenario of "Packing Memories," which involved the boxing of my father's effects to remove from the nursing home. In the vignette, the boxes were going to the nursing home to support the living parent. I wrote earlier in this thesis about this vignette, and the realism of it. I admit that in an earlier draft I gave this scene primacy by placing it as the first vignette, arguing that it was the beginning of a narrative thread. As explained, the narrative became thematic rather than plot-driven, depending on a timeline with a beginning, middle and end. I changed the placement of the vignette so that it fit more directly with the theme of communication greetings.

What lingers with me is at least one scene, noticeable by its absence. That is the scene of the aftermath, once a patient dies. If we are considering care for all people in a person-centred context, then relationships do not end upon death. Some health institutions proceed as if a patient's death is a *fait accompli*, selling the deceased's possessions and keeping the proceedings (Rudgard, 2018), and immediately placing a new resident into the newly-vacated bed (Barooah, Boerner, van Riesenbeck & Burack, 2015). Yet grief from a patient's death may continue with staff and even other residents (also not addressed in this study) and a strong case for considering inclusion in post-mortem rituals could have "positive implications for staff and residents as it validates grief and provides closure" (p. 7).

I became well-acquainted with the staff of the nursing home where my parents lived. I saw the impact of the death of my parents on them. I experienced behaviours, both good and bad, of health care staff. Through my experiences with this work and my family it has become clear that illness is not situated in a single body but in many. Its influences ripple broadly, touching all within the vicinity.

While at University of Toronto I lectured on patient-centred care. I argued that patient-centred care is about focusing on the patient, placing that individual in the centre of a circle, while the remaining supports orbited around the patient. As noted in my literature review, this widely-held belief continues. The patient is always at the point of convergence. I don't think I could return to delivering those lectures. This work has, for me, stirred a substrate of ideas that have remained beneath the surface, not completely silent but certainly muted. I spoke about patient-centred care knowing full well that care for the health provider was also critically important (Epstein, 1999; Van Humbeeck, Dillen, Piers and Van Den Noortgate, 2016; Kuhn and Flanagan, 2017) and yet, in my sessions and in much of the literature I reviewed, the topics seem mutually exclusive. Based on this study and my personal experiences, I now view a successful health care interaction as widely reciprocal, an effort carried out by many individuals. The focus group interviews indicate an overall legacy of joy from the interactions between patients, staff and family, despite examples of horrendous behaviour. Perhaps joy in relationships is the next step in the evolution of person-centred care.

References

- Ahmed, S. (2014). *Willful Subjects*. Durham: Duke University Press.
- Al-Solaylee, K. (2016). *Brown*. Toronto, Canada: Harper Collins.
- Allwood, R., Pilnick, A., O'Brien, R., Goldberg, S., Harwood, R., & Beeke, S. (2017). Should I stay or should I go? How healthcare professionals close encounters with people with dementia in the acute hospital setting. *Social Science & Medicine*, 191, 212-225.
- Alzheimer Society of Canada. (2019). Available from <https://alzheimer.ca/en/on/We-can-help/Resources/Shifting-Focus/Examples-of-responsive-behaviour>
- Alzheimer Society Ontario. (2019). Available from <https://alzheimer.ca/en/on/About-dementia/What-is-dementia>
- Anderson, M., & Wilkinson, L. (2007). A resurgence of verbatim theatre: Authenticity, empathy and transformation. *Australasia Drama Studies*, 50, 153-169.
- Anderson, W. (2007). The colonial medicine of settler states: Comparing histories of Indigenous health. *Health and History*, 9(2), 144-154.
- Arabiat, D., Whitehead, L., Foster, M., Shields, L., & Harris, L. (2018). Parents' experiences of Family Centred Care practices. *Journal of Pediatric Nursing*, 42, 39-44.
- Armstrong-Hough, M. (2015). Origins of difference: Professionalization, power, and mental hygiene in Canada and the United States. *American Review of Canadian Studies*, 45(2), 208-225.
- Ashcroft, R. (2004). Current epistemological problems in evidence based medicine. *Journal of Medical Ethics*, 30, 131-135.
- Ayala, J. & Zaal, M. (2016). A poetics of justice: Using art as action and analysis in participatory action research. *Networks*, 18(1), 1-13.
- Bai, R. (1998). Dances with Mei Lanfang: Brecht and the alienation effect. *Comparative Drama*, 32(3), 389-433.
- Bacopoulos-Viau, A. (2019). From the writing cure to the talking cure: Revisiting the French 'discovery of the unconscious'. *History of the Human Sciences*, 32(1), 41-65.
- Balalykin, D. (2017). Ancient medicine after Herophilus. Part 2. The natural philosophical foundations, theory and practice of the methodic school doctors. *History of Medicine*. 4 (1), 82-99.
- Balint E. (1969). The possibilities of patient-centered medicine. *The Journal of the Royal College of General Practitioners*, 17(82), 269-276.
- Bancroft, J. (2005). A History of Sexual Medicine in the United Kingdom. *The Journal of Sexual Medicine*, 2(4), 569-574.
- Barthes, R. (2010). *Camera Lucida*. (R. Howard. Trans.). New York: Hill and Wang.
- Barooah, A., Boerner, K., van Riesenbeck, I., & Burack, O. (2015). Nursing home practices following resident death: The experience of certified nursing assistants. *Geriatric Nurse*, 36(2), 120-125.
- Barry, J. (2018). The 'Compleat Physician' and Experimentation in Medicines: Everard Maynwaring (c.1629-1713) and the Restoration Debate on Medical Practice in London. *Medical History*, 62(2), 155-176. Retrieved April 7, 2018 from <https://www.ncbi.nlm.nih.gov.proxy.library.brocku.ca/pmc/articles/PMC5883160/pdf/S0025727318000029a.pdf>
- Beer, J., & Steif, E. (1997). *The Mediator's Handbook*. Gabriola Island, Canada: New Society Publishers.

- Belgrave, L., Allen-Kelsey, J., Smith, K., & Flores, M. (2004). Living with dementia: Lay definitions of Alzheimer's disease among African American caregivers and sufferers. *Symbolic Interaction*, 27(2), 199-222.
- Belliveau, G. (2006). Engaging in drama: Using arts-based research to explore a social justice project in teacher education. *International Journal of Education & the Arts*, 7(5), 1-17. Retrieved from <https://eric-ed-gov.proxy.library.brocku.ca/?id=EJ807860>
- Bellonia, E., Facciob, E., Costaa, N., & Iudicib, A. (2014). Health professionals working with persons with dementia. Reflections for new training courses. *Procedia - Social and Behavioral Sciences*, 116, 4700 – 4705.
- Benjamin, C. (1954). A Definition of "Empiricism". *Philosophy and Phenomenological Research*, 15(2), 171-179.
- Bircher, J. (2005). Towards a dynamic definition of health and disease. *Medicine, Health Care and Philosophy*, 8, 335-341.
- Blair, R. (2010). Acting, embodiment, and text: Hedda Gabler and possible uses of cognitive science. *Theatre Topics*, 20(1), 11-21.
- Bloom, M. (2015). "At the end of everything": Confession and Critique in Michel Tremblay's *Damnée Manon*, *Sacrée Sandra*. *English Studies in Canada*, 41(2/3), 43-64.
- Boal, A. (2008). *Theatre of the oppressed*. (C. and M. McBride & E. Fryer, Trans.). London: Pluto Press. (Original work published in 1974)
- Bond, J., Corner, L., Lilley, A., & Elwood, C. (2001). Medicalization of insight and caregivers' responses to risk in dementia. *Journal of Aging Studies*, 6(4), 397-403.
- Boyd, K., Diepstra, H., Hamdani, K., & Lunsy, Y. (2018). Consumer inclusion experience of patients with intellectual and developmental disabilities informs primary care. *Canadian Family Physician / Le Médecin de famille canadien*, 64, 8-11.
- Brecht, B. (1961). On the Experimental Theatre. (C. Mueller Trans.) *The Tulane Drama Review*, 6(1), 2-17.
- Brecht, B. (1996). *Bertolt Brecht journals: 1934-1955*. (H. Rorrison, Trans.). J. Willett (Ed.). New York, NY: Routledge.
- Briggs, L. (2000). The race of hysteria: "Overcivilization" and the "savage" woman in late nineteenth century obstetrics and gynecology. *American Quarterly*, 52(2), 246-273.
- Broadbent, A. (2018). Prediction, understanding and medicine. *Journal of Medicine and Philosophy*, 43, 289-305.
- Brownlow, K. (2000). Lewis Milestone: From transcript to film script. *Film History*, 12, 5-10.
- Brooker, D. (2007). *Person-centred dementia care: Making services better*. London, UK: Jessica Kingsley Publishers.
- Brophy, J., Keith, M., & Hurley, M. (2019). Breaking point: Violence against long-term care staff. *NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy* 29(1), 10-35. <https://doi.org/10.1177/1048291118824872>
- Bruner, J. (2004). Life as narrative. *Social Research*, 71(3), 691-710.
- Byrne, E., Elliott, E., & Williams, G. (2016). Performing the micro-social: using theatre to debate research findings on everyday life, health and well-being. *The Sociological Review*, 64, 715-733.
- Buckley, C., McCormack, B., & Ryan, A. (2018). Working in a storied way—Narrative-based approaches to person-centred care and practice development in older adult residential care settings. *Journal of Clinical Nursing*, 27, 5-6.

- Beach, W., Dozier, D., Buller, M., Gutzmer, K., Fluharty, L., Myers, V. Buller, D. (2016). The Conversations about cancer (CAC) project—phase II: National findings from viewing When Cancer Calls . . . and implications for Entertainment–Education (E–E). *Patient Education and Counseling*, 99, 393–399.
- Berry, L., Davis, S., Godfrey Flynn, A., Landercaspere, J., & Deming, K. (2019). Is it time to reconsider the term “cancer survivor”? *Journal of Psychosocial Oncology*, 37(4), 413–426.
- Calisi, R., Boyko, S., Vendette, A., & Zagar, A. (2016). What is person-centred care? A qualitative inquiry into oncology staff and patient and family experience of person-centred care. *Journal of Medical Imaging and Radiation Sciences*, 47(4), 309–314.
- Canales, M. (2000). Othering: Toward an understanding of difference. *Advances in Nursing Science*, 22(4), 16–3.
- Carless, D., Douglas, K. (2016). Arts-based research – radical or conventional? *Psychologist*, 29(5), 354–357.
- Cascón-Pereira, R., Kirkpatrick, I., & Exworthy, M. (2017). The status of the medical profession: reinforced or weakened by the new public management? *Sanitary Gazette*, 31(3), 273–275.
- Charon, R. (2006). *Narrative medicine*. New York, NY: Oxford University Press.
- Chenail, R. (September 2010). Playbuilding as qualitative research: The play. *The Qualitative Report*, 15(5), 1285–1289.
- Chun, D., & Plass, J. (1997). Research on text comprehension in multimedia environments. *Language Learning & Technology*, 1(1), Retrieved from http://lilt.msu.edu/vol1num1/chun_plass/default.html
- Clark, B. (1974). *Whose life is it anyway?* Chicago, IL: The Dramatic Publishing Company.
- Clifford, C., & Doody, O. (2018). Exploring nursing staff views of responsive behaviours of people with dementia in long-stay facilities. *Journal of Psychiatric and Mental Health Nursing*, 25, 26–36.
- Cogent, R. (2016). Masks as a method: Meyerhold to Mnouchkine. *Arts & Humanities*, 3(1), 1–11. Retrieved from <https://doi.org/10.1080/23311983.2016.1236436>
- Colson, J., & Ralley, R. (2015). Medical practice, urban politics and patronage: The London ‘commonalty’ of physicians and surgeons of the 1420s. *The English Historical Review*, 130 (146), 1102–1131.
- Committee on the Rights of Persons with Disabilities. Convention on the rights of persons with disabilities. New York, NY: United Nations; 2006. Available from: www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx. Accessed 2017 Dec 9
- Connelly, M., & Clandinin, J. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2–14.
- Conquergood, D. (2002). Performance Studies: Interventions and Radical Research. *TDR*, 46(2), 145–156. Retrieved from <http://www.jstor.org.proxy.library.brocku.ca/stable/1146965>
- Copeland, R. (1990). The presence of mediation. *TDR: The Drama Review*, 34(4), 28–44.
- Coret, A., Boyd, K., Hobbs, K., Zazulake, J., & McConnell, M. (2017). Patient narratives as a teaching tool: A pilot study of first-year medical students and patient educators affected by intellectual/developmental disabilities. *Teaching and Learning in Medicine*, 30(3), 317–327.
- Costa, D., Mercieca-Bebber, R., Tesson, S., Seidler, Z., & Lopez, A. (2019). Patient, client, consumer, survivor or other alternatives? A scoping review of preferred terms for labelling individuals who access healthcare across settings. *BMJ Open*, 9(3). 1–16.

- Crenner, C. (2014). Race and laboratory norms: The critical insights of Julian Herman Lewis (1891–1989). *ISIS: Journal of the History of Science in Society*, 105(3), 477–507.
- Cresswell, J. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches*. 4th ed. Thousand Oaks: Sage Publications.
- Cueva, M. (2010). Readers' Theatre as Cancer Education: An Organic Inquiry in Alaska Awakening Possibilities in a Living Spiral of Understanding. *J Canc Educ*, 25, 3–8.
- Curriculum of Caring: A Curriculum of Caring for People with Developmental Disabilities. (n.d.). Retrieved from http://machealth.ca/programs/curriculum_of_caring/
- Davidson, R. (2009). Psychiatry and homosexuality in mid-twentieth-century Edinburgh: The view from Jordanburn Nerve Hospital. *History of Psychiatry*, 20(4), 403–424.
- Dénomme-Welch, S. (2008). The birch bark eaters and the crisis of ethical knowledge in storytelling. *Canadian Journal of Native Education*, 31(1), 56–71.
- Dénomme-Welch, S., & Rowsell, J. (2017). Epistemologies of Silence. *Brock Education Journal*, 27(1), 10–25.
- Desai, A., Wharton, T., Struble, L., & Blazek, M. (2017). Person-centered primary care strategies for assessment and intervention for aggressive behaviors in dementia. *J Gerontol Nurs*. 43(2), 9–17.
- Dewey, John. (1997). *Experience and education*. New York, NY: Touchstone. (Original work published 1938)
- Donmoyer, R., & Yennie-Donmoyer, J. (1995). Data as drama: Reflections on the use of readers theater as a mode of qualitative data display. *Qualitative Inquiry*, 1(4), 402–428.
- Doyle, P., & Rubinstein, R. (2013). Person-centered dementia care and the cultural matrix of othering. *The Gerontologist*, 54(6), 952–963.
- Dyck, E., & Lux, M. (2016). Population control in the “Global North”? Canada’s response to Indigenous reproductive rights and neo-eugenics. *The Canadian Historical Review*, 97(4), 481–512.
- Edson, M. (2001). *Wit*. New York, NY: Faber and Faber.
- Elsaesser, T., & Hagener, M. (2015) *Film theory: An introduction through the senses*, 2nd edition. New York, NY: Routledge.
- Epstein, R. (1999). Mindful Practice, *JAMA*, 282(9), 833–839.
- Etowa, J., Jesty, C., & Vukic, A. (2011). Indigenous nurses' stories: Perspectives on the cultural context of aboriginal health care work. *The Canadian Journal of Native Studies*, 31(2), 29–46.
- Faulkner, J., & Latham, G. (2013) Disturbing stories: Literature as Pedagogical Disruption. *English in Education*, 47(2), 102–117.
- Faulkner, S., (2009). *Poetry as Method: Reporting research through verse*. California: Left Coast Press.
- Fei, F., & Sun, W. (2006). Othello and Beijing Opera: Appropriation as a two-way street. *The Drama Review*, 50(1), 120–133.
- Fish, B. (2018). Drawing and Painting Research. In P. Leavy (ed.), *Handbook of arts-based research* (336–354). New York: Guilford Press.
- Fong, T., Tulebaev, S., & Inouye, S. (2009). Delirium in elderly adults: diagnosis, prevention and treatment. *Nature Reviews Neurology*, 5(4), 210–220. doi:10.1038/nrneurol.2009.24.
- Ford, K., Tesch, L., Dawborn, J., & Courtney-Pratt, H. (2018). Art, music, story: The evaluation of person-centred arts in health programme in an acute care older persons' unit. *International Journal of Older People Nursing*, 13 <https://doi.org/10.1111/opn.12186>

- Fornaro, M., Clementi, N., & Fornaro, P. (2009). Medicine and psychiatry in Western culture: Ancient Greek myths and modern prejudices. *Annals of General Psychiatry*, 8(21). doi:10.1186/1744-859X-8-21
- Frank, A. (2013). *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.
- Franklin, J. (1980). Metamorphosis of a metaphor: The shadow in early German cinema. *The German Quarterly*, 53(2), 176-188.
- Freidson, E. (1985). The reorganization of the medical profession. *Medical Care Review*, 42(1), 11-35.
- Fulford, R. (1999). *The Triumph of Narrative*. Toronto: House of Anansi Press.
- Garrison, J. (1998). Toward a pragmatic social constructivism. In M. Larochelle, N. Bednarz, & J. Garrison. (Eds). *Constructivism and Education* (p.p. 41-60). Cambridge ; New York: Cambridge University Press.
- Gibson, O., Lisy, K., Davy, C., Aromataris, E., Kite, E., Lockwood, C., Riitano, D., McBride, K., & Brown, A. (2015). Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. *Implementation Science*, 10(71), 1-11.
- Gill, F., Leslie, G., & Marshall, A. (2016). Family initiated escalation of care for the deteriorating patient in hospital: Family centred care or just “box ticking”. *Australian Critical Care* 29(4), 195–200.
- Gluyas, H. (2015). Patient-centred care: Improving healthcare outcomes. *Nursing Standard*, 30, (4), 50-57.
- Goldingay, S, Dieppe, P., Mangan, M., & Marsden, D. (2014). (Re)acting medicine: Applying theatre in order to develop a whole-systems approach to understanding the healing response. *RIDE: The Journal of Applied Theatre and Performance*, 19(3), 272–279.
- Grant, D. (2017). Feeling for meaning: the making and understanding of ImageTheatre. *RIDE: The Journal of Applied Theatre and Performance*, 22(2), 186–201.
- Grekul, J., Krahn, H. & Odynak, D. (2004). Sterilizing the “feeble-minded”: Eugenics in Alberta, Canada, 1929–1972. *Journal of Historical Sociology*, 17(4), 358-384.
- Gubrium, A. (2009). Digital storytelling: An emergent method for health promotion research and practice. *Health Promotion Practice*, 10(2), 186-191.
- Guerriero, I., & Correa, F. (2015). Ethics, collective health, qualitative health research and social justice. *Ciência & Saúde Coletiva*, 20(9), 2631-2640.
- Guta, A., Flicker, S. & Roche, B. (2013) Governing through community allegiance: A qualitative examination of peer research in community-based participatory research. *Critical Public Health*, 23(4), 432-451.
- Guyatt, G. Cairns, J. Churchill, D. Cook, D. Haynes, B. Hirsh, J. Irvine, J. Levine, M. Levine, M., & Nishikawa, J. (1992). Evidence-based medicine: A new approach to teaching the practice of medicine. *JAMA*, 268(17), 2420–2425.
- Hall, P., Weaver, L., Gravelle, D., & Thibault, H. (2007). Developing collaborative person-centred practice: A pilot project on a palliative care unit. *Journal of Interprofessional Care*, 21(1), 69–81.
- Harris, A. (2016). *Video as method: Understanding qualitative research*. Oxford, UK: Oxford University Press.
- Harris, A. (2017). Ethnocinema and video-based research. In P. Leavy, (Ed,) *Handbook of Arts-Based Research*. (pp. 437-452) New York, NY: Guilford Publications.

- Hebblethwaite, S. (2013). "I think that it could work but...": Tensions between the theory and practice of person-centred and relationship centred care. *Therapeutic Recreation Journal* 47(1), 13-34.
- Herron, R.V., & Wrathall, M.A. (2018). Putting responsive behaviours in place: Examining how formal and informal carers understand the actions of people with dementia. *Social Science & Medicine* 204, 9–15.
- Hill, C., Knafl, K., Docherty, S., & Santacroce, S. (2019). Parent perceptions of the impact of the Paediatric Intensive Care environment on delivery of family-centred care. *Intensive & Critical Care Nursing*, 50, 88–94.
- Hobbs, K. (1995). *After the Sex*. Unpublished manuscript.
- Hobbs, K. (2000). *FIDO*. Unpublished manuscript.
- Hobbs, K. (2015). *Now*. Unpublished manuscript.
- Hobbs, K. (2017). *The Welland Canal play*. Unpublished manuscript.
- Holloway, K. (2014). Readers Theatre helps student nurses care for the mentally ill. This affective teaching strategy improves students' understanding of mental illness on a deeper personal level. *American Nurse Today*, 9(9), 44-47.
- Illich, C. (2017). The Welland Canal play: Building our own backyard. *The Sound*. Retrieved from <https://thesound.rocks/welland-canal-play/>
- Indick, W. (2002). Fight the power: The limits of empiricism and the costs of positivistic rigor. *The Journal of Psychology*, 136(1), 21-36.
- Jacobus, L. (1989). *The Bedford Introduction to Drama*. New York, NY: St. Martin's Press.
- Jambunathan, J., Chappy, S., Siebers, J., & Deda, A. (2016). Patient-centered care for chronic pain in the emergency department: A qualitative study. *International Emergency Nursing* 24, 22–27.
- Johe, M. & Bhullar, N. (2016). To buy or not to buy: The roles of self-identity, attitudes, perceived behavioral control and norms in organic consumerism. *Ecological Economics*, 128, 99–105.
- Johnson, J., Botorff, J., Browne, A., Grewal, S., Hilton, A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Communication*, 16(2), 253–271.
- Johnson-Cunningham, S. (2018). Beyond gallery walls and performance halls: Five essential steps museums and other cultural institutions must take to center people, communities, and cultivate effective societal change. *Museums & Social Issues*, 13(1), 2-7.
- Johnstone, M., Rawson, H., Hutchinson, A., & Redley, B. (2018). Fostering trusting relationships with older immigrants hospitalized for end-of-life care. *Nursing Ethics*, 25(6), 760–772.
- Julliard, K., Klimenko, E., & Jacob, M. (2006). Definitions of health among healthcare providers. *Nursing Science Quarterly*, 19(3), 265-271.
- Kadri, A., Rapaport, P., Livingston, G., Cooper, C., Robertson, S., & Higgs, P. (2018) Care workers, the unacknowledged persons in person-centred care: A secondary qualitative analysis of UK care home staff interviews. *PLoS ONE* 13(7), 1-20. Retrieved from <https://doi.org/10.1371/journal.pone.0200031>
- Kanellou, V. (2004). Ancient Greek medicine as the foundation of contemporary medicine. *Tech Coloproctol*, 8(S3–S4), DOI 10.1007/s10151-004-0095-z
- Kawin, B. (1987). *How movies work*. New York, NY: Macmillan Publishing Company.

- Knapp, R. (1964). Perceptual interpretation of the social diad: II character of relationship. *Journal of Social Psychology*, 64, 89-100.
- Kolb, D. A. (1984). *Experiential learning: Experience as the source of learning and development*. Englewood Cliffs, NJ: Prentice Hall.
- Kontos, P., Miller, K., Gilbert, J., Mitchell, G., Colantonio, A., Keightley, M., & Cott, C. (2012). Improving client-centered brain injury rehabilitation through research-based theater. *Qualitative Health Research*, 22(12) 1612–1632.
- Kuhn, C., & Flanagan, E. (2017). Self-care as a professional imperative: physician burnout, depression, and suicide. *Journal of Canadian Anesthesia*, 64, 158–168.
- Kurtz, D. (2013). Indigenous methodologies: Traversing Indigenous and western worldviews in research. *AlterNative: An International Journal of Indigenous Peoples*, 9(3), 217-229.
- LaMothe, Ryan. (2013). The spirits of capitalism and Christianity and their impact on the formation of healthcare leaders. *J Relig Health*, 52, 3–17.
- Lamnas, C. (2002). The contemporary pedagogic device: functional impositions and limitations. *Pedagogy, Culture & Society*, 10 (1), 21-38. DOI: 10.1080/14681360200200131
- Leavy, P. (2015). *Method meets art: Arts-based research practice*. New York: The Guilford Press.
- Leyland, A. et al. (2016). Health and health care implications of systemic racism on Indigenous peoples in Canada. College of Family Physicians of Canada, link: http://www.cfpc.ca/uploadedFiles/Resources/_PDFs/SystemicRacism_ENG.pdf
- Leplege, A., Gzil, F, Cammelli, M., Lefevre, C, Pachoud, B. & Ville, I. (2007). Person centredness: Conceptual and historical perspectives. *Disability and Rehabilitation*, 29(20 – 21), 1555-1565.
- Linds, W. (2008). Performing responsibility: Ethical ‘know-how’ through drama facilitation. *Reflective Practice*, 9(1), 101–110.
- Livingston, M., (1991). *Poem-making: Ways to begin writing poetry*. New York, NY: A Charlotte Zolowtow Book.
- Logie, C., James, L., Tharao, W., & Loutfy, M. (2012). “‘We don’t exist’”: A qualitative study of marginalization experienced by HIV-positive lesbian, bisexual, queer and transgender women in Toronto, Canada. *Journal of the International AIDS Society*, 15, | <http://dx.doi.org/10.7448/IAS.15.2.17392>
- Lux, M. (2001). *Medicine that walks: Disease, medicine and Canadian Plains Native people, 1880-1940*. Toronto, Canada: University of Toronto Press.
- Ly, A., & Crowshoe, L. (2015). ‘Stereotypes are reality’: Addressing stereotyping in Canadian Aboriginal medical education. *Medical Education*, 49, 612–622.
- Mackey, S. (2016). Applied theatre and practice as research: Polyphonic conversations. *RIDE: The Journal of Applied Theatre and Performance*, 21(4), 478–491.
- MacRae, N & Pardue, K. (2007). Use of reader’s theater to enhance interdisciplinary geriatric education. *Educational Gerontology*, 33, 529–536.
- Majerovitz, S., Mollott, R., & Rudder, C. (2009). We’re on the same side: Improving Communication between nursing home and family. *Health Communication*, 24, 12–20.
- Makinde, O. (2016). Physicians as medical tourism facilitators in Nigeria: Ethical issues of the practice. *Croatian Medical Journal*, 57(6). 601 -604.
- Maneewong, J., Maneeton, B, Maneeton, N., Vaniyapong, T., Traisathit, P., Sricharoen, N., & Srisurapanont, M. (2017). Delirium after a traumatic brain injury: Predictors and symptom patterns. *Neuropsychiatric Disease and Treatment*, 13, 459–465.

- McKee, M., & Stuckler, D. (2012). The crisis of capitalism and the marketisation of health care: The implications for public health professionals. *Journal of Public Health Research*, 1(3), 236-239.
- Meghani, Z. (2011). A robust, particularist ethical assessment of medical tourism. *Developing World Bioethics*, 11(1), 16-29.
- Mills, M. (1997). Towards a disruptive pedagogy: Creating spaces for student and teacher resistance to social injustice. *International Studies in Sociology of Education*, 7 (1), 35-55. doi: 10.1080/09620219700200004
- Murtinho, V. (2015). Leonardo's Vitruvian Man drawing: A new interpretation looking at Leonardo's geometric constructions. *Nexus Network Journal*, 17, 507-524.
- Newton, W. (2001). Rationalism and empiricism in medicine. *Law and Contemporary Problems*, 64(4), 299-316.
- Neuberger, J., & Tallis, R. (1999). Do we need a new word for patients? *BMJ*, 318, 1756-1758.
- Niessen, T., & Jacobs, G. (2015). Curriculum design for person-centredness: Mindfulness training within a bachelor course in nursing. *International Practice Development Journal* 5(2), Retrieved from <http://www.fons.org/library/journal.aspx>
- Norris, Joe. (2009). *Playbuilding as qualitative research*. California: Left Coast Press.
- Norris, J. (2011). Towards the use of the 'Great Wheel' as a model in determining the quality and merit of arts-based projects (research and instruction). *International Journal of Education & the Arts*, 12(SI 1.7).
- Norris, J. (2016). "Drama as research: Realizing the potential of drama in education as a research methodology." *Youth Theatre Journal*, 30 (2).
- Norris, J. (2017). Reflections on techniques and tones of playbuilding by a director/actor/researcher/teacher. In P. Leavy, (Ed.) *Handbook of Arts-Based Research*. (pp. 288-308) New York, NY: Guilford Publications.
- Norris, J. & Hobbs, K. (2018). *A play in a day: Dramatizing stories of schooling for pedagogical insights*. Presented at the 19th Annual Curriculum and Pedagogy Conference, New Orleans, LA.
- Ondaatje, M. (2002). *The conversations: Walter Murch and the art of editing film*. London, GB: Bloomsbury Publishing.
- Österlind, E. (2008). Acting out of habits – can Theatre of the Oppressed promote change? Boal's theatre methods in relation to Bourdieu's concept of habitus. *Research in Drama Education*, 13(1), 71-82.
- Paget, D. (2010). Acts of commitment: Activist arts, the rehearsed reading, and documentary theatre. *New Theatre Quarterly* 26(2), 173-193.
- Parlee, B. Berkes, F., & the Teetlit Gwich in Renewable Resources Council. (2005). Health of the land, health of the people: A case study on Gwich'in berry harvesting in northern Canada. *EcoHealth*, 2, 127-137.
- Peñaranda, F. (2015). The individual, social justice and public health *Ciência & Saúde Coletiva*, 20(4), 987-996.
- Perry, M., Wessels, A., & Wager, A. (2013). From playbuilding to devising in literacy education aesthetic and pedagogical approaches. *Journal of Adolescent & Adult Literacy*, 56(8), 649-658. doi:10.1002
- Peters, S. (2017). The function of verbatim theatre conventions in three Australian plays. *NJ: Drama Australia Journal*, 41(2), 117-126.

- Petrovich, E. (2018). Accumulation of knowledge in para-scientific areas: The case of analytic philosophy. *Scientometrics* 116:1123–1151. <https://doi.org/10.1007/s11192-018-2796-5>
- Phillips, D. (1995). The good, the bad, and the ugly: The many faces of constructivism. *Educational Researcher*, 24(7), 5-12.
- Physicians Apply. (n.d.). Retrieved from <https://physiciansapply.ca/commskills/the-university-of-toronto-spp-communication-skills-model/>
- Pifarré, M. (2019). Using interactive technologies to promote a dialogic space for creating collaboratively: A study in secondary education. *Thinking Skills and Creativity*, 32, 1–16.
- Poekert, P. (2011). The pedagogy of facilitation: Teacher inquiry as professional development in a Florida elementary school. *Professional Development in Education*, 37(1), 19–38.
- Porsanger, J. (2004). “An Essay about Indigenous Methodology.” *Nordlit*, 15, 105-120, <http://septentrio.uit.no/index.php/nordlit/article/view/1910/1776>
- Porter, A. (2017). Bioethics and Transhumanism. *Journal of Medicine and Philosophy*, 42, 237–260.
- Price, A., Djulbegovic, B., Biswas, R., & Chatterjee, P., (2015). Evidence-based medicine meets person-centred care: A collaborative perspective on the relationship. *Journal of Evaluation in Clinical Practice*, 21, 1047–1051.
- Provenzo, Jr., E., McCloskey, G., Kottkamp, R., & Cohn, M. (1989). Metaphor and meaning in the language of teachers. *Teachers College Record*, (90)4, 551-573.
- Ratnapalan, S. (2009). Shades of grey: Patient versus client. *CMAJ* 180(4), 472.
- Rivers, B. (2015). Narrative power: playback theatre as cultural resistance in occupied Palestine. *Research in Drama Education: The Journal of Applied Theatre and Performance*, 20 (2), 155-172.
- Robinson, J., Callister, L., Berry, J., & Dearing, K. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*, 20(12), 600–607.
- Rondeau, K. (2005). Emergency department overcrowding: The impact of resource scarcity on physician job satisfaction. *Journal of Healthcare Management*, 50 (5).
- Rudgard, O., (2018, January 19). Care homes selling dead residents' possessions and keeping the cash, watchdog warns. *The Telegraph*. Retrieved from <https://www.telegraph.co.uk/news/2018/01/19/care-homes-selling-dead-residents-possessions-keeping-cash-watchdog/>
- Rudy, S. (2014). Consultancy, Disruption, and the Pulse of Pedagogy. *Teaching and Learning Together in Higher Education*, 1(11), 1-12. Retrieved from <http://repository.brynmawr.edu/tlthe/vol1/iss11/12>
- Rybin, V. (2016). The history of medicine in the system of modern humanities. *History of Medicine*. 3(1), 29–37.
- Sackett, D. Rosenberg, W.M.C. Gray, A.M. Haynes, & R.B. Richardson, W.S. (1996). Evidence based medicine: What it is and what it isn't. *BMJ*, 312, 71–72.
- Saldaña, J. (2018). *Writing qualitatively: The selected works of Johnny Saldaña*. New York, NY: Routledge.
- Salvatore, J. (2018). Ethnodrama and ethnotheatre. In P. Leavy (ed.), *Handbook of arts-based research* (267-287). New York: Guilford Press.
- Santana, M., Manalili, K., Jolley, R., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations*, 21. 429–440.
- Sartorius, N. (2006). The meanings of health and its promotion. *Croat Med J.*, 47, 662-644.

- Savitt, T. (2010). Medical readers' theater as a teaching tool. *Cambridge Quarterly of Healthcare Ethics*, 19, 465–470.
- Sawyer, R. & Norris, J. (2013). *Duoethnography*. New York: Oxford University Press.
- Scarnato, J. (2019). The value of digital video data for qualitative social work research: A narrative review. *Qualitative Social Work*, 18(3) 382–396.
- Schoot, T., Hirsch, M., & de Witte, L. (2007). Development of competencies aimed at client-centred care: an evaluation study. *Learning in Health and Social Care*, 6(2), 104–117.
- Shapiro, J., Cho, B. (2011). Medical readers' theater: Relevance to geriatrics medical education. *Gerontology & Geriatrics Education*, 32, 350–366.
- Shelley, M. (1983). *Frankenstein*. New York, NY: Signet Classic. (Original work published 1816)
- Shih, M., Bonam, C., Sanchez, D., & Peck, C. (2007). The social construction of race: Biracial identity and vulnerability to stereotypes. *Cultural Diversity and Ethnic Minority Psychology*, 13(2), 125–133.
- Sinclair, S., Torres, M., Raffin-Bouchal, S., Hack, T., McClement, S., Hagen, N., & Chochinov, H. (2016). Compassion training in healthcare: what are patients' perspectives on training healthcare providers? *BMC Medical Education* 16(169). 1-10. DOI 10.1186/s12909-016-0695-0
- Skrzypek, M. (2014). The social origin of the illness experience: An outline of problems. *Annals of Agricultural and Environmental Medicine*, 21(3), 654–660.
- Small, J. (2007). Postcolonialism, positioning and the use of drama in the teaching of French language and literature. *Caribbean Quarterly*, 53(1/2), 216–221.
- Smith, L. (2012). *Decolonizing methodologies: Research and Indigenous peoples*. London; New York: Zed Books.
- Sontag, S. (1989). *Illness as metaphor and AIDS and its metaphors*. New York. Picador.
- Stapleton, K., & Wilson, J. (2017). Telling the story: Meaning making in a community narrative. *Journal of Pragmatics*, 108, 60–80.
- Stevenson, J. (1999). "The circle of healing." *Native Social Work Journal*, 2 (1). 8–20.
- Stewart, M., Brown, J., Weston, W., McWhinney, I., McWilliam, C., & Freeman eds. (2006). *Patient-Centered Medicine: Transforming the Clinical Method 2nd ed.* United Kingdom: Radcliffe Medical Press.
- Stuttaford, M., Bryanston, C., Lewando Hundt, G., Connor, M., Thorogood, M., Tollman, S. (2006). Use of applied theatre in health research dissemination and data validation: A pilot study from South Africa. *Health (London)*, 10(1), 31–45.
- Sullivan, M. (1986). In what sense is contemporary medicine dualistic? *Culture, Medicine and Psychiatry*, 10, 331–350.
- Sur, R., & Philipp D. (2011). History of evidence-based medicine. *Indian Journal of Urology*, 27(4), 487–489.
- Tanner, J. (2012). Eugenics before 1945. *Journal of Modern European History*, 10(4), 458–479.
- Tanner, S. (2017). Permission to be confused: Toward a second wave of critical whiteness pedagogy. *Journal of Curriculum and Pedagogy*, 14(2), 164–179.
- Thompson, J. (2017). Transhumanism: How far is too far? *The New Bioethics*, 23(2), 165–182.
- Tobias, J., & Richmond, C., (2014). "That land means everything to us as Anishinaabe....": Environmental dispossession and resilience on the north shore of Lake Superior. *Health & Place* 29, 26–33.

- Tobin, M. (2018). Conflicts of interest and the patient–doctor covenant. *Intensive Care Medicine*, 44(10), 1760–1761. <https://doi.org/10.1007/s00134-018-5282-x>
- Toraldo, M., Islam, G., & Mangia, G. (2018). Modes of knowing: Video Research and the problem of elusive knowledges. *Organizational Research Methods*, 21(2), 438–465.
- Toomnan, P., & Intaraprasert, C. (2015). The impacts of attitude towards speaking english on the use of communication strategies by english majors in Thailand. *Theory and Practice in Language Studies*, 5(6), 1151–1158.
- Toombs, S. (1993). The meaning of illness: A phenomenological account of the different perspectives of physician and patient. Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Truth and Reconciliation Commission of Canada. (2015). *The final report of the Truth and Reconciliation Commission of Canada: Reconciliation (Vol. 6)*. Winnipeg: Truth and Reconciliation Commission of Canada.
- USAI: Utility self-voicing access inter-relationality research framework. (2012). Ontario Federation of Indian Friendship Centres, <http://ofifc.org/sites/default/files/docs/USAI%20Research%20Framework%20Booklet%202012.pdf>. Retrieved November 15, 2017.
- Van Humbeeck, L., Dillen, L., Piers, R., & Van Den Noortgate, N. (2016). Grief and loss in older people residing in nursing homes: (Un)detected by nurses and care-assistants? *Journal of Advanced Nursing* 72(12), 3125–3136.
- Valle, J., & Connor, D. (2012). Becoming theatrical: Performing narrative research, staging visual representation. *International Journal of Education & the Arts*, Retrieved from <http://www.ijea.org>
- Vanhoutte, J. (2017). Suzan-Lori Parks's Venus and the Petrarchan Tradition. *Texas Studies in Literature and Language*, 59, 2, 234–267.
- Veland, S., & Lynch, A. (2016). Scaling the Anthropocene: How the stories we tell matter. *Geoforum* 72, 1–5.
- Vettraino, E., Linds, W., & Goulet, L. (2013). Click, clack, move: Facilitation of the arts as transformative pedagogy. *Journal of Transformative Education*, 11(3), 190–208.
- Webb, W. (2018). Rationalism, Empiricism, and Evidence-Based Medicine: A Call for a New Galenic Synthesis. *Medicines*, 5(40), 1–9.
- Westerhof-Evers, H., Visser-Keizer, A., Fasotti, L., & Spikman, J. (2019). Social cognition and emotion regulation: A multifaceted treatment (T-ScEmo) for patients with traumatic brain injury. *Clinical Rehabilitation*, 33(5) 820–833.
- Whalley Hammell, K. (2007). Client-centred practice: Ethical obligation or professional obfuscation? *British Journal of Occupational Therapy*, 70(6), 264–266.
- White, J., Dangerfield II, D., & Grieb, S. (2019). Methodological considerations for conducting focus groups in HIV prevention research among Black men who have sex with men. *Public Health Nursing*, 36, 439–445. <https://doi.org/10.1111/phn.12592>
- Wilson, K., & Rosenberg, M. (2004). Accessibility and the Canadian health care system: Squaring perceptions and realities. *Health Policy*, 67, 137–148.
- Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Winnipeg, Canada: Fernwood Publishing.
- Wing, P. (1997). Patient or client? If in doubt, ask. *Canadian Medical Association Journal*, 157(3), 287–289.

- Wellman, M. (1958). The concept of normal in medicine. *Canadian Medical Association Journal*, 79(1), 43-44.
- Wolgemuth, J. & Donohue, R. (2006). Toward an inquiry of discomfort: Guiding Transformation in “emancipatory” narrative research. *Qualitative Inquiry*, 12(5), 1022-1039.
- Wyer, P., Silva, S., Post, S., & Quinlan, P. (2014). Relationship-centred care: antidote, guidepost or blind alley? The epistemology of 21st century health care. *Journal of Evaluation in Clinical Practice* 20, 881–889.
- Wykurz, G., & Kelly, D. (2002). Developing the role of patients as teachers: literature review. *BMJ*, 325, 818–821.
- Xyst, K. (2019). Constructivism, Dewey, and Academic Advising. *NACADA Journal*, 36(2), 11-19.
- Yoshida, M. (2007). Playbuilding in a Japanese college EFL classroom: Its advantages and disadvantages. *Caribbean Quarterly*, 53, (1-2), 231-240.
- Zola, E. (1986). Naturalism (A. Bermel, Trans.). In E. Bentley (Ed.), *The theory of modern stage* (pp. 331-372). Middlesex, England: Penguin Books.
- Zuidegeest, M., Delnoij, D., Luijkx, K., de Boer, D., & Westert, G. (2012). Patients’ experiences of the quality of long-term care among the elderly: comparing scores over time. *BMC Health Services Research*, 12(26), 1-10. Retrieved from <http://www.biomedcentral.com/1472-6963/12/26>

Appendix A: Transcript Responses

2			THEME	SCENE	TITLE
3					
4	quote or subject matter	A/R/Tor	transcript	page #	response/punctum
5					
6	"The grey no"	DS	TBI	10	
7	code Lavender	DS	TBI	8	spiritual distress
8	"All the emotional and verbal and sexual [violence] goes on constantly. So we don't call a code white for that."	DS	TBI	2	
9	"on-site training is 90% of the learning"	DS	TBI	11	preparation
10	"Day 1 was an education right here"	DS	TBI	10	

11	"I'm an emotional person. This is a daily reality"	DS	TBI	4	letting go/accommodation
12	"Get the hell out of here and go back to Ottawa where you belong."	DS	TBI	15	
13	I don't come here to work to get hit... his family is forever grateful"	DS	TBI	12	thankfulness/gratefulness
14	They've lost their filter	DS	TBI	2	
15	I think it's the call of duty	DS	TBI	8	control
16	chemical restraints - best for patient?	DS	TBI		ethical restraint
17	Okay, let's talk about options here	DAW	Feb1a	1	
18	what were they like before	DAW	Feb1a	4	
19	is there something you've always wanted to do?	DAW	Feb1a	5	
20	understanding the patient's perspective	DAW	Feb1a	3	
21	some people misuse their power when given power	DAW	Feb1a	9	
22	including them in the conversation	DAW	Feb1a	4	
23	"Panic moment"	DAW	Feb1a	1	
24	less inhibited	JN	VetFam	4	
25	memory a heck lost	JN	VetFam	4	idea
26		JN	VetFam	4	letting guard down
27		JN	VetFam	4	doing the right thing???
28		JN	VetFam		family > communication < staff
29	decorating mom's room	JN	VetFam	4	
30	keeping engaged	JN	VetFam	3	shadow screen, wheel chair behind person in front
31	teaching the rules/culture	JN	VetFam	8	is this patient centred?

32	what did you do in the war?	JN	VetFam	3	losing inhibition
33	knowing back story calms her down	JN	VetFam	2	What to pack?
34	Ask her about Nova Scotia	JN	VetFam	2	short term/long term
35	embarrassed, who cares, we're used to it	JN	VetFam	5	
36		JN			quickie: same question 10 times
37		JN			reflective practice, group discussion, training
38	family expectations	JN	1b	5	wheelchair/shadow screen
39		JN	1b	6	reputation vs. high expectations
40	longevity, retention, what keeps you here	JN	1b		
41	why isn't my mother...	JN	1b	4,5	
42		JN	1b	5	no closure/reconciliation
43	"We are all just human beings"	NG	VetFam	5	
44	"You know, my loved one, just not the loved one I used to know"	NG	VetFam	18	
45	"You're not here to preach"	NG	VetFam	4	
46	"No one wants to be here. No one wants to be in a hospital"	NG	VetFam	11	
47	"Did I make the right decision?"	NG	VetFam	4	
48	"Care for you may be different than care you need"	NG	VetFam	4	
49	how people are approached	AR	1b	17, 18	
50	"The squeakiest wheel gets the grease/oil"	AR	1b	6	
51		AR	1b		Client's Mom
52	Edsel analogy	AR	1b		how to handle unrealistic expectations

53		LD	VetFam		build a relationship
54		LD	VetFam		connection
55		LD	VetFam		personal narratives
56	pictures lead to memory stimulation	LD	VetFam		
57	treated as an object... that'll turn anyone off	LD	VetFam		
58	"we're all on the same journey"	LD	VetFam		
59	"so you leave traumatized by your own behaviour"	LD	VetFam		
60	"every day we get knocked down a little bit"	LD	VetFam		
61		LD	VetFam		veterans
62	"people are receiving information in different ways"	LD	VetFam		
63	baby talk	LD	VetFam		
64	never talk to them in third person	LD	VetFam		
65	they can't be managed	LD	VetFam		
66	they're not good, passive participants	LD	VetFam		
67		LD	VetFam		pictures, stories
68	An Escape. (from what?)	LA	TBI		
69	"We don't call code white for that, but maybe we should"	LA	TBI		
70	what point does it become too much for staff to handle	LA	TBI		
71	No filter - "Were they always this way?"	LA	TBI		
72	ethical tension	LA	TBI		professional vs. personal
73	"How many times have you decided to leave?"	LA	TBI		

74	What is care?	LA	TBI		physical, psycho-social
75	Care + Control (or lack of)	LA	TBI		
76	The Grey No	LA	TBI		
77	On-the-site training (90%)	LA	TBI		
78	Advocate for what you need	LA	TBI		
79	To code white or not to code white	LA	TBI		
80	"my dad was a one-woman man"	KH	LTC 1	8	
81	"she doesn't remember but I still feel bad"	KH	LTC 1	13	
82	"I can wipe your bum bum" "How are we today?"	KH	LTC 1	7	baby talk
83	"His dentures are like stars. They come out at night."	KH	LTC 1	6	
84	"He's on the edge of dementia but he hasn't lost his mind."	KH	LTC 1		
85	"I have room for veterans who are teachers - they teach me how to age"	KH	Feb 1b	36	
86	"They think they're going to die"	KH	Feb 1b	25	
87	"I am the welcome sign"	KH	Feb 1b	12	
88	"What's the training?"	KH	Feb 1b	4	
89		KH	Feb 1b	24	Cognitive Floors
90	Edsel, the old car	KH	Feb 1b	11	
91	Blaming others	KH	Feb 1b	10	families blame professionals and professionals blame families
92	"Families, families, families"	KH	Feb 1b	7	
93	"managing expectations"	KH	Feb 1b	6	
94	"My mother would never decline"	KH	Feb 1b	5	

95	"Get him walking, get him walking, get him well"	KH	Feb 1b	20	consensus
96	I want to speak to the supervisor. I want to know who's in charge"	KH	Feb 1b	5	
97	Environment. Environment. Environment. Everything.	KH	Feb 1b	23	
98	"I want to be that friendly face."	KH	Feb 1b	21	
99	"You're not here to preach."	KH	Feb 1b	18	
100	"Not always. Not always. Not always."	KH	Feb 1b	14	
101		MM	discussion - PC care		Finding the time
102		MM	discussion - PC care		What is fine?
103		JN	discussion - PC care		I like my job
104		JN	discussion - PC care		breakfast time/time to get up/my mom always eats at 8 am
105		JN	discussion - PC care		breakfast time (clock visual)
106		JN/KH	discussion - PC care		pay/visit
107		JN/KH	discussion - PC care		one issue/visit
108		JN	discussion - PC care		paid visitors
109		JN	discussion - PC care		"how can you negotiate with people who are not themselves"
110		JN	discussion - PC care		holistic= family and environment
111		SS	discussion - PC care		Moving Tables
112		SS	discussion - PC care		Negotiate by Screaming
113		LD	discussion - PC care		Counting the minutes- watching the clock tick tick
114		LA	discussion - PC care		Can only talk about one thing, make another appointment
115		LA	discussion - PC care		Where is my choice? What are the options not ultimatums

116		LA	discussion - PC care		What do you do when you don't have a family doctor?
117		LA	discussion - PC care		The Waiting List
118		LA	discussion - PC care		control vs. care
119		BK	discussion - PC care		Family doctor vs walk-in clinics vs hospitals
120		BK	discussion - PC care		What choice do I have in my health?
121		NG	discussion - PC care		Power of Compassion
122		JN			quickie: same question 10 times
123		JN			control can lead to aggression
124		JN			They're not present, they're past
125		JN			Treat(ed), Treat(ment)
126		JN			Family-centred care
127		JN			Does it really matter?
128		JN			Ignoring person in wheelchair
129		JN			Crisis Prevention Institute
130		JN			needs: hospital bed, wheelchair
131		JN			Care, car(ried), car, cart, carriage,
132		JN			when to carry, when to be carried (self-care)
133		MM	Feb 1a	5	Tell me More
134		MM	Feb 1a	15	Who Cares? Who Carries?
135		MM	Feb 1a	9	Don't lose your cool. Don't raise your voice. Stay calm. Listen. Make sure you are safe. Locate exits. Ask for help if you need it.

136		MM	Feb 1a	7,8	Behaviour documentation and tracking: ABC- Antecedent, Behaviour Consequence -Special ed. Strategy
137		MM	Feb 1a		Listen (to the needs), Understand (the needs), Act (accordingly)
138	"They know when you are tense- it makes them more agitated"	MM	Feb 1a	12	
139		MM			Identities
140	"mocking your profession"	LD	Whyte acute care 1	5	
141	12 hours with a patient!	LD	Whyte acute care 1		
142		LD	Whyte acute care 1	13	cultural components
143	"I stay... for the firsts"	LD	Whyte acute care 1		
144		LD	Whyte acute care 1		language
145	"Be able to advocate for what you need"	LD	Whyte acute care 1	8	
146	"Were they always this way?"	LD	Whyte acute care 1	3	
147	"You just sort of keep going"	LD	Whyte acute care 1	4	
148	friends/family agenda for therapy - getting better	LD	Whyte acute care 1	5	
149	The Grey No"	LD	Whyte acute care 1	10	
150	"When do we take them out of the restraints? Families are watching and upset and they are looking to nursing to advocate to that patient"	LD	Whyte acute care 1	1	
151	rationalizing (the person's behaviour) and allowing	LD	Whyte acute care 1	3	
152		LD	Whyte acute care 1		control - who has it, who does not?
153	are you annoying them? Are you being therapeutic? Are they enjoying? Is your work effective? Do they want this?	LD	Whyte acute care 1	6	unknown territory
154	"They've let go of a lot that isn't necessary"	LA	VF	4	

155	"Seems that they can let their guard down and much freer than where we have to live in these so sheltered lives, very sad in some way, but important in another"	LA	VF	4	
156	"They're not good passive participants. It changes. They have to be actively participating."	LA	VF	4	
157	direct questioning	LA	VF	4	
158	"Things are faster, noisier, and there's more challenges	LA	VF	1	
159	"Where you found there was a disconnect and... when there was a connect in finding conversations"	LA	VF	3	
160	"Listen to understand, not to fix."	SS			
161	"If this was my mom or dad, would I want others to treat them?"	SS			
162	Personal questions: open-ended	SS			
163	create familiarity in an otherwise unfamiliar situation	SS			
164	"They sense it" (low staffing ratios)	BK	Feb 1a	12	
165	"Treating them like an individual"	BK	Feb 1a	4	What does that mean?
166	"listening to know their story"	BK	Feb 1a	4	
167	"tell me more"	BK	Feb 1a	5	
168	"You have to be in their reality"	BK	Feb 1a	10	
169	use sympathy and humour	DS	LTC1	6	
170	"You've got to treat a person as a total individual	DS	LTC1	7	
171	Baby talk with veterans	DS	LTC1	7	
172	"He's on the edge of dementia, but I tell you he hasn't lost his mind, and that's what we have to keep in mind. They have many, many lucid moments."	DS	LTC1	9	expectations: mom thinks he's fine, daug

173		DS	LTC1		What do you say?
174		DS	LTC1	5	Patient who asks the same question multiple
175	"But it's hard to convince him that he's not being ignored, you know, and so then he gets agitated and his language can be somewhat defensive."	DS	LTC1	5	
176	"I doubt myself sometimes, and even feel guilty for making certain decisions. I try and discuss everything with him to the extent possible, but somehow you just have to make hard-core decisions"	DS	LTC1	13	
177	"What do you do when your patient is 3/4 of a century older than you and is not lucid? How do you relate to that person?"	DS	LTC1	12	
178		DS	LTC1		who are you, really?
179	"How do you respect the dignity of someone when they don't respect yours?"	DS	LTC1	10	
180	"Yes. You're going to be different with different people... caring is figuring out what the other person needs intellectually."	DS	LTC1	9	
181	"I'm going to live in your world"	KH	Feb 1a	10	pretending to be another
182	"What do you like to do for fun?"	KH	Feb 1a	6	An easy question
183	"Three words that describe you"	KH	Feb 1a	5	what patient says, what family says,
184	"To know their story"	KH	Feb 1a	4	
185	"Being in the moment"	KH	Feb 1a	3	
186	"This is your nurse. She can never be your friend."	KH	Feb 1a	23	
187	no dead ends	KH	Feb 1a	13	
188	"Just clapping his hands..."	KH	Feb 1a	11	does he want to participate or be
189	"Little wins"	KH	Feb 1a	24	

190					A Toxic Mix
191	"document behaviour... not by labelling but by describing"	KH	Feb 1a	8	phone-line- "I hear he's difficult. Pass it on" leading to I hear y sundowns. Pass it on'

Appendix B: Log Book/Journal

March 5, 2019 Mirror Theatre pre-session

- Read through transcripts from focus groups (3 hours). 4 sets of transcripts totalling 92 pages
 - Used pink marker to identify themes and stories and yellow marker for potential titles
 - Made notes in pencil in possible approaches to facilitating story emergence
- Made notes on questions I have for Joe Norris on approaches
 - Should we portray patients?
 - Should I provide set of questions from larger research study?
 - Should we approach as a creation for making suggestions for staff or for leaving questions that may generate conversations... or both?
- Evening session will entail distributing transcripts to Mirror Theatre A/R/Tors. They will be asked to highlight possible themes, stories and titles – puncta - and write ideas on blank cards. Question: *what speaks to you or surprises you?*
- I should be part of this questioning process as it is clear the more I know the less I know. Maybe share this idea with the Mirror group.

- Require markers, pens, blank cards and transcripts (to be distributed and collected at beginning and end of session. A/R/Tors will be asked to sign name on transcript. They will also be required to sign a confidentiality form.

Personal response to transcripts

The stories shared were very familiar considering my experiences with both my parents. I recognize approaches that I have used with my mother and father, as well as approaches that the staff members in my parent's nursing home have utilized. By no means emotionally distraught, I was moved by the stories, however, particularly when specific examples of struggles and successes were discussed. For example the discussion on sexual behaviour struck close to home, as I had witnessed both my father and mother become sexually assertive/aggressive. I was surprised that there was not as much discussion about the presence of long-term memory even though there was much discussion about discovering who the patient is and reasons that may be behind responsive behaviour.

The discussion on person-centred care interested me as I used to teach that subject at University of Toronto. The one thing that was possibly hinted at but not explored was that person-centred care involves consideration the health professional's well-being and voice.

I noted a difference of opinion between the health worker interviews and the family interviews. Each blamed one another (at times) for not fully understanding the context of either the patient or the environment (hospital). Further to that, often staff disagreed on the best practice approaches in care.

Post-Mirror Theatre session

It was a rocky start to the research. I initially had nine A/R/Tors (10 including Joe Norris) but after completing other Mirror Theatre business some people had to leave to attend to personal issues and subsequently future scheduling conflicts were discovered. Essentially, the first order of business for this project was establishing schedules. We have agreed upon four Tuesday sessions from 6 pm- 9 pm (3 hrs) and a succeeding Saturday in April to video the devised vignettes.

After scheduling I led the group in a theatre game I created called “Pass the information” in which one must state their full name to another who repeats the name, then provides their full name which is repeated by the first person and only then can the “information” (in this case a stuffed alligator) be passed from first person to second. I chose this exercise because it reflects the communication struggles in health care. This exercise refocused the group and provided a few surprises. Many ongoing members of Mirror Theatre did not know (or at least know how to pronounce) last names, much less middle names. People had fun and the energy became positive.

We only had a few minutes to speak about the project. I identified communication as being a huge theme in the transcripts. I spoke about my process in going through the transcripts, how I highlighted themes, stories and titles. People signed confidentiality forms and I asked them to look through transcripts (either paper or electronic). It was made clear these transcripts are confidential and extreme care must be taken. Finally, self-care was discussed. It was noted that everyone has responsibility to note their own reactions and if severe issues emerged for an A/R/Tor that one should speak with someone, either a professional from Brock or one of the Mirror Theatre members who have training in mental health first aid. People appeared eager to get started on this project. We adjourned the session on a positive note.

March 12, 2019 – Session #1- Pre

This session with Mirror Theatre is the first full three-hour session. I call it session #1. The plan is to start reading paper copies of the transcripts (they were not uploaded to a web platform). Time is limited and I do not wish to spend three hours looking through transcripts as I fear we will become bogged down by over-thinking. I will break up the three hours to avoid monotony, the death of creativity.

The **Goal** of this session is to introduce the A/R/Tors to the concepts of patient-centred care and the struggles in long-term and acute care.

I will begin with a warm-up – WordBall. We begin in a circle. The starting person chooses a single word and sends it *across* (points and eye contact) to someone else. The receiving person immediately chooses a word that responds to the received word, and sends it either to their *right* or to their *left*. That receiver immediately responds with a different word and sends it *across*. The pattern is across, left or right, across, left or right, across.

I am choosing this warm-up to focus the A/R/Tors while asking them to react instantly – without thinking – to a word. As I move into the research tonight I will be asking them to find themes, stories, titles that they instantly connect to. No thought. I will ask them to recognize the Punctum, a wound or “personally touching detail” (Barthes, *Camera Obscura*, p. 43)

As they read through the transcripts I will ask them to write down the words, themes, etc. on cards provided. They will initial each card. They can also highlight in marker. We will then pass the transcripts around. We will do this for an hour. Afterwards, we will go through the cards and discuss them. We will divide the cards into themes, titles, words. We will discuss anything that did not make sense in the readings. We will do this until about one hour left. Then

we will divide into groups, taking a card that the group agrees upon as something it wishes to work on. We will begin to improvise a scene.

Post

Session proceeded as planned. Most people only completed one transcript. In order to ensure all transcript information was discussed, I asked people to discuss what was relevant to them. Since every transcript (except one) was read by two people a conversation between those two people became immensely informative, as they built off of one another and on occasion discussed how they experienced similar bits of data differently. For example, there were questions about the “Grey No” and its meaning. Over thirty cards were produced. I did not go through them with everyone due to a time factor. In order to facilitate the process I shall create an excel spreadsheet that indicates the writing on the cards, the A/R/Tor initials, the transcript identifier and the page numbers.

The description of punctum seemed to resonate. It may be important to see how important punctum is through this entire process as we are moved, swayed, and attending to the personally touching details found in the transcripts.

With 30 minutes left I broke the A/R/Tors into two groups: Dani Shae, Joe and Nadia in one, and Abby, Dawson Lindsay and Lindsay in the other. The Dani Shae group immediately connected with the idea of a code white and began discussing different aspects of that story (do you call a code white – help- or not?). The Abby group went through the cards, each A/R/Tor discussing what they found meaningful, finally deciding on a single option after considering many. Both groups produced rough versions of what could be powerful scenes.

March 23, 2019 – Session#2 – Pre

This session continues the work we began in the first session. There will be Mirror Theatre members new to this specific research. We will have to catch up. Included in the catch-up will be an orientation to what person-centred care is.

We will begin with a check-in. What have people been doing throughout the week? And a reflection on the video shoots a few days earlier from another project. I will then take them through a warm-up called “Meet & Greet”. In this warm-up people walk around and when told they will find someone and shake hands. They will wander again and when told find someone else and “saw” (in tandem imaginatively saw a piece of wood together). They will wander again and when told they will link arm and arm and “swing your partner”. This should generate focus and energy. I am choosing this exercise in order to connect the actors to the concept of how we introduce ourselves to each other. This is a topic that is in the transcripts.

We will then do another transcript-reading session – one transcript only – a new one per person. I will ask them to fill out cards. We will then go through cards and go through the excel spreadsheet I created that includes comments from the previous session.

We will then break into groups and create new vignettes. Ideally I would like to create another four vignettes.

March 23, 2019 – Session#2 – Post

Participants: Mike, Lindsay, Lindsay, Sumer, Dawson, Joe, Candace

A good session with lots of discussion. It followed what I had planned with a few differences. I discussed person-centred care (and other care modules including doctor centred/patriarchal and consumerist model) with a visual:

PERSON-CENTRED CARE

- Person-centredness means addressing the person's specific and holistic properties
- Person-centredness means addressing the person's difficulties in everyday life
- Person-centredness means the person as an expert: Participation and empowerment
- Person-centredness means respect the person 'behind' the impairment or the disease

[LePlege, A. et al. (2007). Person-centredness: Conceptual and historical perspectives. *Disability and Rehabilitation*. 1555-1565.]

As we began to discuss the kinds of care people began to tell stories. At this point I found we needed to write down details on cards. An important note for myself: I must be ready for spontaneous discussions by having blank cards and pens nearby.

Everyone took another transcript and went through it. After half an hour with the transcript we regrouped and discussed. At this point Joe discussed his need to go deep, focusing on one or two pages, or even a word (as an example he discussed care/carry/car/cart/carriage). Joe also shared how this work moved him and gave him cause to reflect on his attitudes toward dementia, particular in relation to it affecting him down the line. We discussed self-care.

In the final 15 minutes we broke into two groups. Joe, Candace, Mike and Sumer worked on one scene which I was able to video. The other three worked on a scene which they did not have ready to video.

For myself I am now considering three things:

- Developing scenes based on themes
- Forming scenes that will provide impetus for discussion

- Visualizing how scenes might be videotaped

March 25, 2019 – Session#3 – Pre

We are half-way through the sessions. Two more after this and then we need to shoot.

We will start with greetings and an exercise. One possible exercise may be: “Look what I’ve got” in which one mimes holding something and shows it to another. The second person identifies it – “You’ve got a (bunny)” – “Yes, I’ve got a bunny” and passes it over to the second person who has to change it into something else and then show another. I am choosing this exercise because it relates to the idea of entering into another’s world, perhaps the world of someone with dementia.

We will then move into working on the two scenes from the previous session. New people can join in the two groups.

Once those scenes are completed we will look at the excel spreadsheet with all of the comments, identifying themes, storylines, titles.

Ideally I would like to finish the session with a total of eight vignettes.

March 25, 2019 – Session#3 – Post

The session began with frustration due to external events that had nothing to do with this study. The A/R/Tors spent time sharing their frustration – letting it all out – in order to move on with the next thing. Without acknowledgment of the frustrations we would not have been able to engage in creative activity.

We worked on the scenes from the previous week and videoed them. We then moved to viewing the excel spreadsheet to identify what other topics stand out as something that should be viewed. The discussion was lively. There is a focus on Code White and the question to call or not to call security. This code has made its way into three scenes. Is that too much?

We also discussed through the spreadsheet what stories haven't been told yet. I made notes as people spoke on things that had meaning to them. These notes I added into the spreadsheet as potential scenes.

We spent the last fifteen minutes working on two new scenes which were then videotaped.

I placed the spreadsheet onto the Mirror Theatre invited Facebook page so that members can view the potential scenes if they like.

April 2, 2019 – Session#4 – Pre

As we move into session four I realize this is our last opportunity to develop new scenes. Session five (next Tuesday) will be about honing the developed scenes, followed by a Saturday video shoot.

I will start with greetings and an exercise to focus. Possibly "Look what I've got" or, if energy is required something else such as the name game.

We will then revisit the excel spreadsheet and see what scenes have relevance to the group. There are a couple of scenes I think I would like to see attempted. One has to do with passing information on a patient – labelling vs. describing. Another has to do with identifying injuries on the health professional's body.

Ideally I would like to develop four more scenes so we have choices for the final roster of vignettes.

April 2, 2019 – Session#4 – Post

Mike, Lindsay D., Dani-Shae, Dawson, Bernadette

We had a smaller number of A/R/Tors due to illness and other personal reasons. This worked to our advantage. After a warm-up (“Look what I’ve got”, intended to exemplify the imaginative entry into another’s life/belief) we immediately began working on scenes. I went through the possible scenes we discussed last week, generating some conversation and interest. Three scenes sparked interest and so we divided into groups of three, each group taking a scene. We began with a structured way of devising but we found that each of the identified scenes spun into other scenes. This is an example of the kind of creativity that occurs when people are allowed the freedom to play. As a result we developed six scenes, two more than I expected. There are a few more scenes that I would like to try next week.

Joe Norris and I had a conversation about process and dominant voices. Both Joe and I are familiar with this work. We have read and re-read the transcripts. Joe participated in the focus groups. Both of us think about this work throughout the week, between sessions. We have more knowledge of the raw data (stories). This leads to a danger of dominance. Do our voices supersede the voices of the other A/R/Tors? For my part, I follow a system of facilitation in which I always ask the other A/R/Tors their opinions first and for the most part remain quiet, with the exception of a comment here or there. As much as possible I watch the scenes form, trusting in the expertise of the seasoned A/R/Tors and the established Playbuilding process. As a

D/A/R/Tor, I do my best to stay out of the way until I see it might be necessary to add my opinion. I also anticipate inserting myself more once I view all of the videos, after some distance.

April 9, 2019 – Session#5 – Pre

I spent the afternoon going through the scenes we have developed. I intend to show the videos of each scene tonight to hone. There are at least two scenes that are missing: labelling as opposed to describing and the discussion between a nurse and family member on the shared abuse they have received from the patient. In both cases we are looking for the human underneath the system.

Once we do a warm-up (will decide based on energy level) we will first work on the devised scenes from the last few weeks. After that we will work on any scenes that we think we have missed. We will also track what props, costumes, items are necessary. My attempts to get a clinical setting at Brock nursing and McMaster's Niagara campus have failed. We will work in the studios this Saturday.

April 13, 2019 Pre-shoot

There are still some scenes that require work. We have approximately two hours (9-11) of rehearsal before Brad completes his camera set-up. I have asked Joe to ensure that all the videos of the rehearsed scenes are up on the private Facebook page so people can re-familiarize themselves with the scenes before Saturday. Scenes that still require significant work are: "When is it not Normal/ Body Map", "Labels/The Pipeline", "Thank you", "Tic Toc" and all the scenes of "Let it Go". I have created a shot list. Our working title for this video is "The Bigger Picture". Other options discussed with Joe are "Shadows" and "Transitions". This is the shot list:

*NOTE: SHOT LIST HAS BEEN REMOVED BECAUSE IT HAS ALREADY BEEN
REPRODUCED IN APPENDIX C*

I have sent this list to Brad, our videographer. I have arranged the shooting so that we can start with all the scenes that include the shadow screen and then tear it down for the final three scenes.

I have made shot decisions (long, medium, direct address) to fit the style – eg., metaphor, realism – and the intent – eg., camera is patient – of the devised scenes.

In typical Mirror Theatre fashion we will be improvising on the spot, figuring things out as we go along. Since we haven't learned lines but rather have developed a sense of the scenes (with the exception of a few verbatim moments) we must continue to devise in the moment. This is fine so long as we maintain intent. Also, my shot list above does not address all questions, such as who is performing certain roles. This is not terribly frightening. I worked as a production assistant, a grip, a props master, a stunt man and a second assistant director on commercial shoots. There is always improvisation in filming (with apologies to Hitchcock), no matter what the degree of planning might be. I trust the Mirror Theatre actors.

April 13, 2019 Post-shoot

It was a long day. I believe it was successful. Brad, our videographer, used three cameras for coverage. The middle camera videoed the master shot. Brad adjusted the other cameras to suit the blocking. The shadow screen looks good in playback. With the exception of two scenes where a lav mic (lavalier microphone, a remote sound recorder usually attached to a performer's body) was used, the sound was recorded through the built-in microphones on the cameras.

We shot twenty vignettes. More than expected. We were set to record fifteen. Five vignettes were completed and/or created on the spot, all based on efforts and ideas from previous sessions. This is a testament to the performers in Mirror Theatre.

Once the rough edits by Brad are completed I will look and decide the order of the vignettes. I haven't figured out if I need to create a plot-based narrative or a theme-based narrative. I think either possibility is viable.

Appendix C: Shot List

SHOT LIST – APRIL 13, 2019

The Bigger Picture

Shadows

Transitions

Scene	Cast	Set, Props, Costumes etc.	Camera
Mis(sed)understanding	Joe, Dawson, ?		Shadow, long shot
Grey No Mush up drugs	Sumer, Rosa, Abby	Apple Sauce Ketchup ,holder Mortar and Pestle, Medicine Cup, SS	Shadow, Medium/long shot
When is it not Normal?	Candice, Sumer, two shadow, laser pointing people	8 laser pens, SS	Shadow, long/wide shot
Meant to Tell You Responsive Behaviour Code Lavender	Joe, DSB, Candice, Lindsay	SS, Scrubs, Wheel Chair	Shadow, Medium shot
What if I called it earlier	Sumer, Dawson, Lindsay	SS	Shadow, medium shot
How to Approach Patient Centered Care	Joe, Sumer (Bernadette), Candice,	SS, Table	Shadow, medium shot

	Mike		
Wait and Accommodate No (grey No?) Family Expectations	Joe, Candice, Mike	SS, Wheeled Table	Shadow left Right
The Rowdy Bunch	Mike, Joe, Dawson, Sumer Abby, Candice	SS	Walks into shadow screen Door Slam, wide shot
Bath Day (Shower) Communication	Kevin, Dawson, DSB	Clap, Day 1, Day 2 Clip Board, Wheel Chair Chaise lounge, SS	Medium Long, Shadow
Let it Go (3 scenes)	Joe, Lindsay, ?	Photo, 2 chairs, tray, SS	Shadow, Medium
Tic Toc	DSB Bernadette, Lindsey, Lindsay	Tray, Photo Frame, Book, Scrubs, SS	Split Frame, Shadow
ADDED SCENE ON SATURDAY: Interviews Family	Dani-Shae, Rosa, Lindsay, Candice, voices: Lindsey, Abbey, Bernadette		Shadow, Wide shot
ADDED SCENE ON SATURDAY: Interviews Staff	Mike, Dani-Shae, Joe, Candice, Bernadette, Abbey, Kevin, voices: Dawson, Lindsey, Rosa, Sumer, Lindsay		Shadow, Wide shot
ADDED SCENE ON SATURDAY: Interviews – What Makes You Stay	Mike, Dani-Shae, Lindsay, Rosa, Sumer, Bernadette, Joe, voices: Abbey, Lindsey, Kevin, Dawson, Candice		
ADDED SCENE ON SATURDAY: Thank You	Dani-Shae, Rosa, Lindsay, Lindsey, Abbey, Mike, Dawson		Shadow, Wide shot, Three separate medium shots
Labels	Bernadette, Abbey, Mike, and Lindsey Only two required?)	Folders	Medium shot, close up (POV)
Packing Memories (Thanks for the)	Mike, Bernadette	Suitcase, Jacket, Scarf, NY Hat, Key Chain, Photo Album, Cindy Chair. Table Cloth, Clutter, Coat Rack, Book Shelf,	Wide shot

		Curtains, Kleenex	
Turntable Etiquette	Lindsey, Lindsay, Dawson, Abby	None, All Black/T-shirt	Close up and long shot

Appendix D: Editing Notes and Sequencing

Working Title- Understanding Person-Centred Care: Finding Dignity Within the Shadows

Other Potential Titles

Kevin

“I am the Welcome Sign”: Discussing Person-Centred Care
 The Human Centre
 In the Company of Each Other
 Let’s Get Real

Joe

Setting the Stage for Best Practices
 Best Practice? Let’s Start the Conversations
 Punctum,
 Let’s Talk
 Time makes us cut corners
 We’re all in this Together
 Learning the Codes, Rules of Engagement
 Close Encounters of the Health Care Kind
 The Bigger Picture
 Shadows
 Transitions
 Beat the Clock
 It’s About Communication
 For the Good of All
 Forecast: Not so Sunny

Notes:

- Each vignette should be its own chapter so viewers can jump back to revisit a scene if desired.
- The video stays on the question long enough to be read in voice over. If facilitator wishes to pause then that is their prerogative. Otherwise the video continues all the way through.
- This document is a compilation of eleven documents. It does not reflect the long-term process of editing the video.

	Kevin, Joe, Brad	Time Code	Notes <i>(these combined notes are a collaboration between Joe and Kevin)</i>
1	Mirror Theatre		<i>White lettering against black background</i>
2	Presents		<i>White lettering against black background</i>
3	Understanding Person-Centred Care: Finding Dignity Within the Shadows		<i>Panels of images from video surrounding title</i>
4	Voice greeting and explanation		<i>The narration scrolls as V.O. of narration takes place.</i>
5	Turntable Etiquette	<i>1:14-1:55</i>	<i>A good way to start video. Puts the viewer in the seat of the patient through use of point-of-view</i>
6	Question: First impressions linger. How would you respond to the greetings in the last vignette? How would you respond if you were a family member or patient? How would you change the greeting if you were a staff member?		<i>V.O. reading question</i> <i>Superimpose question over still image of last vignette</i> <i>Text imposed over first frame of next vignette. This will be the convention for all Title Cards.</i> <i>Text of question slowly fades - this is to be the convention for all questions or statements.</i>
7	Patients coming to long-term care facilities have a series of hellos and goodbyes. We interviewed staff and family members to get a sense of these interpersonal relationships. Here is some of what we found.		<i>V.O. statement</i> <i>Superimpose statement over still image of over first frame of next vignette. This will be the convention for all Title Cards.</i> <i>The question is formed in such a way to inspire collaborative discussion rather than oppositional.</i>
8	Family Interviews	<i>2:25-3:10</i>	<i>Minimal editing. Sometimes a switch between camera distances. At no point do we lose images of silhouettes since their perspective is of prime importance.</i>
9	Title Card: The Loooooong Goodbye		
10	Packing Memories	<i>3:40-6:48</i>	<i>Edit only to focus on details. Opening wide shots establish overall space then use footage that narrows to support conversation, such as coat on a hook or a hat or drawing pencils</i>
11	Question: Whenever a new patient arrives, everyone's world changes. How did yours or how might yours?		<i>V.O. reading question</i> <i>Superimpose question over still image of last vignette</i> <i>Using "did" and "might" places the examples in the past and future. This opens the opportunity to think about adjustments (if need</i>

			<i>be) for the present.</i>
12	Title Card: Let's Talk...		
13	Question: How could communication structures be improved between family and staff? What have you experienced?		<i>V.O. reading question Superimpose question over still image of last vignette</i>
14	Breakfast Offerings	7:14-9:24	
15	Communication on Bath Day	9:27-11:20	
16	Labels	11:22-12:57	<i>Once again use of point-of-view puts viewer into position of being the patient.</i>
17	Title Card: Time		
18	Question: Time can move forward, backwards, and sometimes it stands still. When do you live in the present, when do you live in the past, when do you live in the future? Are you aware of when other people live with a different clock than yours? The following vignettes consider time in different contexts.		<i>V.O. reading question Superimpose question over still image of last vignette It is an abstract question. Hopefully the vignettes provide concrete examples. This discussion could lead into staff having to address multiple issues, or family members sitting with a dying loved one.</i>
19	Tic Toc	13:26-15:55	<i>This requires significant editing. Scenes must juxtapose to create a sense of many spaces (room, hallway, clock) and pacing changes. The clock should always be metaphorically close. Nix the idea of putting the clock in the upper corner as a count-down. It is better to have it fade-in and -out in order to create tension</i>
20	Meant to Tell You/Code Lavender	15:58-16:36	
21	What if I Called It Earlier?	16:38-17:18	
22	Statement: Staff told us in the interviews about their ongoing commitment to achieve “therapeutic rapport” and to understand what the patients are going through.		<i>V.O. reading statement Superimpose statement over still image of upcoming vignette – include researchers and staff.</i>
23	Staff Interviews	17:45-18:19	

24	Title cards: Understanding Another's Perspective		<i>Person-Centred Care has many elements. Each title card has tried to reflect an element in some fashion. This one is possibly the most important. It refers to empathy. Give the viewer the opportunity to understand what is going on in another person's life.</i>
25	Question: So much goes on behind the scenes. If you could talk about One thing you do for a patient or loved on, something no one knows, what would it be?		<i>V.O. reading question Superimpose question over still image of last vignette</i>
26	Mis(sed)understanding	<i>18:32-19:53</i>	<i>This vignette ends with a direct address to the camera. This breaks the convention that the viewer is a patient. The impetus for this switch comes from a frustration within the health care staff. It is Brechtian in its technique.</i>
27	Grey No	<i>19:54-20:56</i>	<i>Another Brechtian technique at the end, in which a character comes in out of nowhere to explain the complexity of power-of-attorney.</i>
28	The Rowdy Bunch	<i>20:57-22:09</i>	<i>The punctuation to this scene is the door slam. Ensure that is audible.</i>
29	Should It Be Normal?	<i>22:10-23:41</i>	
30	Title Card: How Do You Cope?		
31	Question: We all have ways of coping. If we don't care for ourselves, then how do we care for another?		<i>V.O. reading question Superimpose question over still image of upcoming vignette</i>
32	What Makes You Stay?	<i>23:53-25:00</i>	<i>This is a single-shot. No need to edit as the flow was smooth. All silhouettes are always visible.</i>
33a	Let it Go—Pen Click	<i>25:01-25:53</i>	<i>The next four vignettes are connected by a single nurse character. This is the only time in the video that we have a continuing character, therefore we identify all four as 33. The vignettes 33a, 33b and 33c have the same rhythm. Discussion with patient then cut to discussion with someone else (staff or family). The final 33 vignette (33d) has a direct address to the viewer. This is Brechtian just like "Mis(sed) understanding"</i>
33b	Let it Go—Ray of Sunshine	<i>25:54-27:34</i>	<i>Cut nurse's denial of patient's reality. This response is not advocated in dementia care.</i>

33c	Let it Go—Code Lavender	27:35-28:30	
33d	Let it Go—Ray Monologue	28:31-28:47	
34	Statement: Even in the shadows, dignity can be found.		<i>V.O. reading statement. Superimpose statement over still image of upcoming vignette.</i>
35	Thank you	29:00-30:51	<i>Multiple views, multiple discussions, multiple perspectives. End with a wide shot to show everyone saying “Thank you”. The final statement is a direct address to the camera. The “thank you” could be for anyone: patient, staff, family.</i>
36	Title Card: Credits		<i>Different music. More hopeful.</i>